

Please cite the Published Version

Croston, Michelle (2018) An interpretative phenomenological analysis of how HIV nurses elicit patients' concerns. Doctoral thesis (PhD), Manchester Metropolitan University.

Downloaded from: <https://e-space.mmu.ac.uk/620581/>

Usage rights:  Creative Commons: Attribution-Noncommercial-No Derivative Works 4.0

Enquiries:

If you have questions about this document, contact openresearch@mmu.ac.uk. Please include the URL of the record in e-space. If you believe that your, or a third party's rights have been compromised through this document please see our Take Down policy (available from <https://www.mmu.ac.uk/library/using-the-library/policies-and-guidelines>)

An Interpretative phenomenological analysis of how HIV Nurses elicit patients' concerns

Michelle Croston

A thesis submitted in partial fulfilment of the requirements of the Manchester Metropolitan University for the degree of Professional Doctorate

Faculty of Health, Psychology and Social Care
Manchester Metropolitan University

Department of Health Professions
2017

Contents page

Abstract

Acknowledgements

Chapter One: The Joe Effect: The Real Beginning

1.1 Introduction	15-18
1.2 Setting the scene	18
1.3 The current context of HIV care and the role of the nurse	19-26

Chapter Two: Literature Review

2.1 Person centered healthcare	29-31
2.1.1 Patient centered care and nursing	31-37
2.1.2 Patient centered care and HIV nursing	38-43
2.2 The concept of being	43-46
2.3 The concept of authenticity in the nurse patient relationship	46-51

Chapter Three: Methodology

3.1 Epistemological position	52-58
3.2 What is interpretative phenomenological analysis (IPA)?	58-59
3.2.1 Phenomenology and IPA	59-60
3.2.2 Epoche – My thoughts and understandings	60-63
3.2.3 Hermeneutic existential phase – Heidegger	63-65
3.2.4 Hermeneutic circle	66
3.2.5 An overview of idiography in IPA.	66-68
3.2.6 What are the methodological considerations associated with IPA?	68-70
3.2.7 What does double hermeneutics mean?	70
3.2.8 Criticisms of IPA	71-72
3.3 The role of reflexivity	72-73
3.4 Poetry	73-77
3.5 Final reflections on using IPA	78
3.6 Methods	78
3.6.1 Participants and recruitment	78-80
3.6.2 Data collection	80
3.6.2.1 The interview process	80-81
3.6.2.2 The interview schedule	81-83
3.6.2.3 Transcribing	83-84
3.6.2.4 Ethical considerations	84-85
3.6.2.5 Reflexive journal	85-86
3.6.2.6 Pre understandings	86-88
3.6.2.7 Analysis quality and validity	88-90

Chapter Four: Introduction to Analysis

4.1 My research participants pen portraits	97
4.1.1 Harry	98-99
4.1.2 Orla	99
4.1.3 Erin	100
4.1.4 Shauna	100-101
4.1.5 Niamh	101-102
4.1.6 Louis	102
4.1.7 Zayn	103

4.1.8 Holly	103-104
4.1.9 Alannah	104
4.1.10 Iona	105
4.2 Can you show me how to be ...	106-112
<u>Chapter Five: Findings</u>	
5.1 A way of being: HIV nurses experience	113-128
5.2 The nurse patient relationship	128-141
5.3 Factors that impact on authentic care	142-154
<u>Chapter Six: Discussion</u>	
6.1 Introduction	155-157
6.2 Overview of research findings	157-161
6.3 Discussion of findings	161-162
6.3.1 HIV nursing – Way of being	162
6.3.1.1 Introduction	162-163
6.3.1.2 Being as care	163-165
6.3.1.3 Being as authentic	165-168
6.3.1.4 Being as aware	168-170
6.3.1.5 Being as freeing	170-171
6.3.2 Therapeutic relationships and the influence on patient centered care	171-173
6.3.3 Why is providing care for people with HIV different?	173-176
6.4 What does this add to the current body of knowledge on HIV nursing?	176-178
6.5 What are the implications for practice?	178
6.5.1 Self awareness	179-181
6.5.2 Reflections within clinical practice	181-186
6.5.3 The concept of a HIV person centered nursing framework	186-191
6.5.4 What are the key implications of the findings for the wider nursing agenda	191-193
6.6 Summary	193
<u>Chapter Seven: Happy Endings</u>	
7.1 Future research	198
7.2 Reflections on the research process	198-199
7.3 Concluding thoughts	199-202
Reference list	203-219
<u>Appendix</u>	
Appendix One: The participant information sheet	220-223
Appendix Two: The Interview schedule	224-225
Appendix Three: An example of a participants transcript	226-240
Appendix Four: Examples of copies of Ethical Approval	241-242

Abstract

Aim

The aim of the research was to explore how Human immunodeficiency Virus (HIV) nurses elicited patients concerns. Through the use of participants' stories from clinical practice, the research explored how therapeutic relationships developed between the HIV nurse and patient. Through the use of story telling the nurses were able to explore situations in which they had dealt with strong emotions of patients with complex needs.

Background

HIV care has evolved as a result of the development of effective antiretroviral therapy and has now been categorised as a long term condition. As a result of advances in the medical treatment of HIV, the role of the HIV nurse has also developed. It is important to explore the impact of these changes for the role of HIV nurses in clinical practice when eliciting the concerns of their patients.

Approach

Data were gathered using semi-structured interviews from ten nurses who volunteered to be involved in the study. The nurses were interviewed on a single occasion and were encouraged to share stories from their own clinical practice. Interpretative phenomenological analysis was used and underpinned by Heideggerian hermeneutic phenomenology in order to analyse the data that was generated through the interviews. Alongside the participants stories I have also presented reflexive accounts from my own practice, which have helped in the development of the research

Findings

The findings revealed that the process of eliciting patients' concerns were a complex and multifactorial process. Analysis of the interviews revealed three superordinate themes:

- A way of being: HIV nurses' experiences;
- The nurse-patient relationship; and
- Factors that impact on authentic care.

Through these reflexive accounts from the HIV nurses' clinical practice, a framework was developed for an HIV nursing philosophy that was patient-centred, non-judgemental and enabled nurses to elicit patient's concerns.

Conclusion

The research adds to the growing body of knowledge on the positive relationship that developed between the HIV nurse and patient. It also adds to the increasing body of knowledge of what it means to work in a patient centred way in order to elicit the concerns of patients.

Acknowledgements

There are so many people to thank and dedicate this work to as they have all played their part in making this dream a reality. To Dr Chris Wibberley and Dr Kirsten Jack, my inspirational supervisors, who believed in me when I didn't believe in myself. Thank-you for always pushing me that bit further in my thinking.

To my wonderful daughter, Harriet, your support, patience and understanding enabled this to happen. To my mum, dad, grandma and closest friend Laura, for encouraging me to always reach for the stars and being there to pick me up when it didn't quite work out.

To all the participants and patients whose stories made this piece of work possible. You continue to inspire me and encourage me to be the best I can be.

Finally, in loving memory of my grandad who sadly never had a chance to read this. Thank you for advising me to make work my passion so that I would never work a day in my life.

Chapter 1: The Joe Effect: The Real Beginning

My thesis initially started off written in a very traditional structure introduction, literature search, methodology and it reflected the 'traditional' approaches to presenting doctoral work that I had read. As my confidence grew as a researcher and as the significance of my research came to light through reflexive practice and supervision. I decided to integrate my story of being an HIV nurse, using the memories I had of providing care for a significant patient (Joe). The memories of caring for Joe would come to mind as I listened to my participants' stories from practice: or when I was listening to the radio that could also trigger, how, as a nurse I had been able to elicit Joe's concerns and in doing so become a more patient centred nurse. Joe's case was one, but a central one, in shaping the way I work as a nurse.

Throughout my career I have often heard colleagues and managers motivating staff by saying that one person can make a difference, whilst referring to me, a nurse making a difference to someone's life. What people didn't consider was that a patient could also make a difference to a nurse's life. For me, that person was Joe. I no longer provide nursing care in the same way as a result of my experiences with Joe. Prior to meeting Joe, my background was very medically focused and I couldn't understand why anybody who was HIV positive would choose not to take HIV medication. I was convinced that any reason for not taking treatment could be 'fixed' and it was my job to do just that, to highlight the reason for them not taking treatment and to fix them; for the patient, for the patient's sake.

Through my interactions with Joe, I learnt, albeit the hard way, an alternative way to provide care. To reach this alternative way to provide care I had to question everything I had ever been taught in order to develop a genuine style of nursing that provided the care that Joe required.

I began working with Joe in the summer of 2007, at the time he was a similar age to me and we shared lots of common cultural interests. His diagnosis had come, as a shock to him and it would appear that since his HIV diagnosis he had pressed the self-destruct button and set in place a path of choices that would ultimately lead to his death. My role in the situation was to support him and explore his decisions around treatment. From the start he was a challenge and I had to use every skill I had to keep him engaged.

Initially I approached the situation medically, with facts and consequences. When I saw this approach was not working, I had to take a step back and re-evaluate the situation.

I remember being called on to the ward by the senior medical doctor to 'fix' a patient and get him to take treatment. I remember walking into his room and asking if I could speak to him. He responded by saying that I could stay and told me to sit down. Once I had sat down, he said that I could stay as long as I didn't discuss or mention treatment. I remember sitting down and thinking "What now?" ... So, we talked and watched *Diagnosis Murder*. Which is a mystery medical crime drama about a medical doctor and his son, (a homicide detective) who solved crime. Watching *Diagnosis Murder* became a theme. I would go in to 'watch TV' and we would end up discussing lots of issues, such as his hopes, goals and wishes for the future.

I remember some of our conversations starting very lightly and ending in very deep, enlightening conversations. I remember feeling frustrated at times, powerless and questioning what I was doing, what I believed in and what good nursing care meant.

As a result of Joe, and in my attempt to try and reach him or get him to reconsider his decision, I booked myself on course after course, hoping to find 'something' that would help him. The sad thing is, I have learnt that I had what he needed all along; to be there for him; not to judge him and be genuine with him. When I reflect on my early experiences with Joe, I realise I had created a therapeutic relationship, one that allowed both of us to develop.

This revelation came when I was undertaking some motivational interviewing training. Joe had asked about the books that I was carrying around. I proudly told him the books were about motivational interviewing. Joe seemed interested, so I explained what it was, secretly thinking that this would be my chance to use the technique. After I had finished explaining motivational interviewing to Joe, he turned to me and smiled "Chelle that won't work with me, you know that. All I need is you to be here for me. Like you always are."

Now with more knowledge concerning Joe, I question my intentions. Was I trying to 'fix' him by booking myself on course after course, trying to get all the skills I needed to get him to take treatment? I honestly don't think so. I think my intentions were more fear based, scared that I was letting Joe down by not knowing how to help. I genuinely cared for Joe and although I did not understand his decision not to take treatment and ultimately die as a result, I respected him enough to support his decision, however personally challenging that was for me.

I had on numerous occasions been very honest with Joe and clearly stated that although I would prefer a world where Joe was alive and taking treatment, I realize that, it wasn't about what I want. It was Joe's life and I would support his choices to the best of my ability.

Joe's decisions have caused me to shed many tears, as I have watched him suffer, physically and psychologically with his disease as it progressed, and the general distress of living with HIV. His decisions have also sent me in to battle with many of my medical and nursing colleagues, as I defend Joe's choices. At times, I have felt like a bodyguard, protecting him from well meaning junior doctors who try and persuade him to change his mind.

I am not on this journey alone with Joe, I share the distress that caring for Joe brings with Joe's clinical psychologist (Pat). I have had many supportive conversations with Pat as we have both tried exploring strategies to help Joe and shared a sense of failure that comes with this process. This support has been invaluable in developing my nursing practice and has been far more beneficial to Joe than any of the skills based courses that I had attended.

Without supervision from Pat, I would not have been able to support Joe so well and think I might have suffered burnout and even left nursing. I remember one session with Pat where I was quizzing him about what other training I could go on. Pat turned to me and said "there is no magic skill or new technique or course you can go on to change the outcome of this. I have also been asking my supervisor for skills and training I have never found it either". He added 'you (we) have managed to keep Joe engaged with us and been able to support him for over 10 years. You can make a list of the amount of professionals Joe has disengaged with, yet he chooses to stick with us, so how can you or I have let him down?' There was a sense of disappointment that there were no other skills that I could gain to help with Joe's treatment, Pat also sensed this frustration which was a massive relief to me. But, Pat was right, Joe did always stay engaged with us. Joe had been struggling for years with treatment and eventually decided that he could no longer face the thought of one more attempt to take treatment. For Joe coming into an acute ward was his worst nightmare as he

was faced with well meaning doctors and nurses trying to work out why he was not on medication. He faced constant attempts to scare him with threats of a slow and painful death if he did not start treatment.

Myself and Pat had spent many hours supporting Joe with information regarding his health in an attempt to respect his wishes and alleviate some of his fears around dying. This support led to Joe being referred to the palliative care team for advice and support to ensure Joe had as symptom free death as possible; and to die in the place of his choosing.

Just after Christmas week, I received a phone call from Joe, which went something like this:

Joe: pleased you have answered your phone. I have had air, land and sea rescue looking for you

Joe had an extremely sharp and witty sense of humour and often rang multiple departments looking for me, before trying my mobile phone or office phone. Due to Joe's HIV there was a degree of HIV dementia and subsequent cognitive impairment.

Me: (laughing) Lovely to hear from you. Did you have a good festive season?

Joe: Kind of. I have been really busy, that's why I am phoning you.

Me: Oh that sounds interesting tell me more...What have you been up to ...

Joe: well I met Dr Death. Chirpy fella, especially as that's all he does ALL DAY ... talk about death

Slightly concerned about Joe's cognitive impairment I seek clarification.

Me: Dr Death? . (realising Joe's sense of humour I answer my own question)
aarrgh Dr Long, the palliative care doctor?

Joe: Yep that's the fella. Anyway decided enough is enough..I'm off treatment and I can't do it again .. I really did try this timeand well... no easy way to say this but the funeral is booked ...all paid for ...

I am in shock ...overwhelmed and trying to process what an almost hysterically happy Joe was saying.

Me: What do you mean? Joe? are you ok ...slow down ...I am trying to follow you

Joe: Never felt better. 'Chelle you know how I have struggled and I just can't keep doing this ... I have met with the funeral director ... he was the one that did my mum's funeral and I have sorted everything out ... I thought you would like to know.

Me: It sounds like you have everything sorted

Joe: Yep ... just wait there a minute...

In the background I hear lots of banging and then music playing. It's one of my favourite Wham songs. I hear George Michael singing, "You do the jitter bug... You do the jitterbug.. you put the boom, boom, into my heart". Joe comes back to the phone. In the past we have often joked about the memory tests he is exposed to on admission to hospital and he suggested that instead of asking him when the First World War was (as the standard test asks) we should try asking him things he has a fighting chance of knowing, like what year was Wham's last Christmas number one? I am reminded of this conversation and Joe's sense of humour as I hear Wham playing in the background.

Joe comes back to the phone giggling like a school child. It's lovely hearing him so happy, although I am worried this is due to the fact that his cognitive functioning is declining as a result of the HIV affecting his brain.

Joe: Do you like this song?

Me: I love it

Joe turns up the volume and we both start singing along 'wake me up, before you go, go, I'm not planning on going solo, wake me up before you go go:' We stop and laugh.

Joe: This is what I am having playing as I enter the church
I stop laughing and almost feel like I stop breathing, I can't think straight or process
what comes next, my head feels like it is whirling.

Joe: I'm having blah, blah playing in the middle and blah, blah as you all walk
out. Wait a minute I'll find you the tracks ...

Me: Joe, Joe ... don't go wait ...talk to me a minute ...
I begin talking really fast as I process what has just been said.

Me: You're having this as you go into the crematorium?

Joe: Yes that's right and do you remember the video to this?

Me: Yes I think so, which part do you mean?

Joe: The t-shirts they wear

I smile to myself. Of course I do. I was slightly relieved we were not listening to more
funeral music.

Joe: 'Choose Life' T shirts

Me: Yes that's right, white t-shirt with black Choose Life lettering

Joe: I've ordered you one ... well ordered a few ..for the funeral and would like
you to wear it ..It's all in the plan and arrangements.

My laughter turned to tears. Tears that are rolling down my face, which I am trying
desperately for Joe not to sense. Slightly choked, I go on ...

Me: I'm not sure. I'm not sure I can.

Joe: Please it would mean the world to me if you did.

I am not sure I remember what my response was. I don't think I did answer. Joe kept
talking about the arrangements for the funeral. An hour later, I hang up traumatised
by the experience, informing Joe I would see him next week for our regular coffee
and catch up meeting.

I have a mixture of feelings when I remember this conversation. This was Joe's personality and sense of humour and yet there was so much irony in his request.

I imagined standing next to his dad and brother (who I have met on numerous occasions) in my 'Choose life' t-shirt, looking at the words and thinking if only you did Joe, choose life, and then I wouldn't have to stand, shoulder to shoulder with your family and mourn your loss. I wouldn't be left with a mixture of emotions, feeling I could have done more, that I should have done more, left with my sense of loss for a wonderful patient and the loss of the nurse I used to be. Then happy that I had been part of your journey and always kept you at the centre of my nursing care, even if that meant wearing a 'Choose Life' T-shirt as your last request. Glad that I had grown as a nurse as a result of the Joe effect

During the final few months of Joe's life, my developments in practice made me question whether I still wanted to be a nurse. During this time I got tired of being chastised for being 'too close' to Joe. A well-meaning medical colleague informed me that I would be devastated when Joe died. I got tired of defending my practice and frustrated with people. If it is acceptable for me to cry at a sad film, then why was it not acceptable for me to have an emotional response if someone I have cared for died? Why do I have to shut my emotions off to be a professional?

On reflection, my numerous years of working with Joe and the lessons I have learnt as a result of this process formed the basis of my reasons for undertaking this research.

Throughout my career as a HIV specialist nurse my practice has been influenced by a number of different patients and their stories. Whilst undertaking my research these patients' stories came to mind and highlighted the significance they had on shaping

my practice. These stories and the impact that they have had, were contained within my reflexive practice and enabled me to think more honestly about what had led me to develop my research interests. With this in mind, I could have filled my thesis with multiple tales from my practice, of patient stories and the part those stories played in shaping the nurse I am, thus developing the research into an autoethnography. Instead I have chosen to focus on Joe as he was the most significant patient for me as he challenged my very being and made me question every belief about nursing I had held.

Why start my thesis with Joe? I had considered where I would introduce Joe within my thesis before reaching the decision to start my thesis with the story of Joe. I was a different nurse and person after meeting Joe. My whole way of being was altered following my experiences with Joe. This experience made me question who I was as a nurse and person, therefore Joe was a significant turning point for me in developing patient centred compassionate care. I had thought about presenting my introduction before telling the story of Joe, in line with more traditional thesis. However I did not want to distract you, the reader, from the real beginning of my research journey; therefore I have attempted to minimize introduction comments to those necessary to provide context.

Throughout my thesis the story of Joe and my research journey will be presented. In order to tell my story I will be using different approaches, reflective, narrative and thematic, in order to enable the story to unfold, allowing multiple layers of the story to be represented throughout the thesis.

1.1 Introduction

When I first started my research journey I wasn't aware just how significant my experiences of providing care for Joe had been. I had taken note of Devereux (1967) who commented that the choice of subject area for research can be of personal significance to the researcher, whether they realize it or not. When I first started my doctorate journey, I am not sure that I appreciated how significant my research was to me. I developed a story to explain why I was carrying out my research and implied that it was going to add to the evidence base of previous projects that I had developed. I felt that by doing this, I could tell people what I thought they wanted to hear and in doing so justify what I was doing. Through the process of reflexive practice and research supervision my project's significance was brought to light. These experiences will be shared with you throughout this thesis in a reflective manner.

Looking back to the earlier stages of my research development, I felt I had a lot to prove to others and myself, namely that I was a competent nurse, researcher and academic. I had faced a lot of criticism from peers for even contemplating undertaking my professional doctorate, which fuelled my desires to be 'good enough'. There is a general belief within my practice area that 'good' nurses are not academic and have more practical qualities, the 'good' nurses do as opposed to think. This belief becomes obvious when nurses say to me 'I'm more practical and not academic like you.' It took me a long time to build up the courage to enquire if they had considered that they might need to reflect on their approach to practice and patient care. It took me even longer to feel comfortable with my own practice and to understand that my thinking enabled me to be a 'good' nurse.

These internal thought processes led me to overlook the real reasons behind my research motivations. Due to my own insecurities as a researcher and academic, I

felt I had overly justified the rationale for my research study. I hid behind a communication course that I had developed stating that my doctoral research was to look at what skills experienced nurses used in practice, and which skills they felt were most useful when dealing with complex patients. These findings would then be incorporated into the skills based communication course to make it more meaningful for the nurses undertaking the course. Looking back at my communication skills course and the lessons that I learnt as a result of developing the course, I realized that there was something missing; but I couldn't work out what that missing element was: I hoped, through interviewing experienced colleagues about their experiences, that this would come to light. My rationale for the research study seemed plausible and allowed reflexive time, to work out what I was doing and what was really driving my research.

Whilst undertaking the professional doctorate I was Chair of the National HIV Nurses Association (NHIVNA). Through my work as NHIVNA chair I engaged with patient groups in order to ensure the education and research that we, as an organisation were developing, had the patients' voice throughout. During my NHIVNA tenure, I was in a fortunate position to lead on a project, with an expert multidisciplinary team and patient representatives, to develop a tool to assist healthcare professionals to elicit patients' concerns; called the Wellness thermometer (Croston, Petrak and Ustainowski 2017). The Wellness thermometer was evaluated well, by both healthcare professionals and patients.

The development of the tool has helped to fuel my passion for finding ways to elicit patients' concerns both at a local, (clinical) level and also in my position as NHIVNA chair. Looking back, I have always been interested in this subject, speaking to colleagues and role models at a national level, to learn how they elicited patient concerns, in order to then replicate this in a training format for more junior members of staff. I think the biggest motivation for having a research focus on eliciting patients'

concerns is my desire to provide the best care possible for patients, based on reflections from clinical practice, and the need for patients to be at the centre of that practice.

Fortunately, the way in which I had designed the research, enabled me to explore the nurses' experiences of eliciting patients' concerns, through the use of their experiences with patients. I hadn't realised at the time that this was a very fundamental part of how I learnt about issues from practice. I could read books and journal articles that outlined various different concepts and care issues, but it is spending time with patients that helps to cement this learning and add meaning. As a result of hearing nurses retell their patients' stories, I could see how the theories I had been reading (around stigma, living with HIV, adjusting to a HIV diagnosis, adhering to life long treatment) related to the patients' experience. The process of linking theory to practice through patients' experiences increased my knowledge of care for people with HIV and enabled me to incorporate this learning into my clinical practice.

My research interviews, through the use of sharing patients' experience, enabled me to reach a deeper understanding of how nurses elicited the concerns of people living with HIV and helped bring into the forefront the real motivating factors for undertaking my research.

This thesis is made up of seven chapters. The opening chapter begins with the background to the research project and sets the scene. The second chapter reviews the literature that relates to my research, highlights my decision-making process when exploring the literature, and how the literature relates to my research. Chapter three introduces my methodology, Interpretative Phenomenological Analysis (IPA). Within chapter three I explore why I have chosen IPA as my research approach,

what IPA is, and the criticisms of using IPA as a research methodology. I also explore the role of reflexivity and my rationale for using poetry to introduce my research participants to the reader. Chapter three ends with a discussion of how I utilized the research design exploring the methods utilised within my research. Chapters four and five explore my research data, and I explain how I have analysed the data and the challenges I faced using IPA as a methodology. I do this before sharing my research findings. Within chapter six, I discuss the findings and their implications for practice. Chapter seven is the final chapter, where I share my concluding thoughts and implications for practice and research.

1.2 Setting the Scene

Throughout my career I had always been interested in learning more about how nurses elicited patients' concerns in order that they can meet their care needs. This interest developed from a series of practice-based observations that occurred throughout my career. My motivations to learn more about this area of care had arisen as a result of providing care for patients in very complex situations and then helping them to make sense of their experience. The reflections from my practice sparked an interest in patient centred care and research, and stoked a passion to provide evidence based compassionate care.

Since starting my career, I have had a special interest in working with patients who are human immunodeficiency virus (HIV) positive. This interest developed and subsequently led to my current role as a HIV specialist nurse over the past 10 years. During my career, I have observed first-hand how this disease has evolved and the impact that this has had on patients.

1.3 The current context of HIV care and the role of the nurse

The treatment of HIV and the associated acquired immunodeficiency syndrome (AIDS) has changed dramatically since the advent of the first antiretroviral therapies (ART), and subsequent combination therapies (Antiretroviral Therapy Cohort Collaboration, 2008;Thompson et al., 2012). There have been improvements in efficacy and tolerability, as well as simplified dosing requirements for combination therapies, including the arrival of once-daily single-tablet regimens (STR).Today, life expectancy for a 20 year old receiving ART in the US, UK and Canada is virtually the life expectancy of a 20 year old person in the general population, i.e living into their 70s or even 80s (Samji et al., 2013).

This important gain in life expectancy creates new challenges concerning the management of people living with HIV (PLHIV). The care paradigm has changed from managing patients with a relatively acute infectious disease and poor treatment outcomes to that of managing a long-term chronic condition (Degroote et al., 2013). New challenges arising from this change may include factors that impact on patients' quality of life (QoL) and health-related quality of life (HRQoL), such as the burden of lifelong adherence to ART (Corless et al., 2013). Unlike people living with acute or terminal illnesses patients, with chronic conditions such as HIV, potentially face a lifetime of contending with both the effects of their illness and the impact of the treatment. Where management of a patient with an acute or terminal illness may need to be focused on short-term distress, patients with a chronic disease course may require their long-term well being to be monitored.

With medical advances, and this change in disease trajectory, came a shift in the needs of the patients that I cared for. The nature of the consultation began to shift in focus from being about physical health complaints, side effect management and multi tablet treatment regimes, to concerns about long term living with HIV,(with a more

psycho-social focus). These changes in patients' needs are also reflected within the literature with the QoL of PLHIV being divided into psychological, interpersonal, spiritual, and environmental concerns (Basavaraj et al., 2010; Tran et al., 2012). Alongside the burden of disease, adverse effects of treatment for HIV may also contribute to a worsening of a patient's HRQoL.

HRQoL has been associated with both physical and clinical outcomes in HIV management, including immune status, viral load, and opportunistic infections (Tran et al., 2012). Importantly, HRQoL has a reciprocal relationship with adherence to therapy. Patients with poor adherence may experience less improvement in HRQoL (Corless et al 2013; Degroote et al 2013). Conversely, side effects of treatment may negatively impact on HRQoL and reduce adherence to treatment (Webb and Norton, 2004; Mannheimer et al., 2005). Therefore it would seem important that HIV care should be delivered in a way that improves QoL issues and HRQoL outcomes for patients. This, branch of literature I familiarised myself with was, how do we achieve improved outcomes for patients within clinical practice?

The importance of effective communication between healthcare providers (HCPs) and patients should not be underestimated. Patient satisfaction, adherence to treatment, and health outcomes are all affected by the effectiveness of patient-HCP communication (Laws et al., 2012). The strength of the relationship between patients and HCP depends on factors such as participatory — or collaborative — decision-making, general communication, and trust (Schneider et al., 2004).

It is common to find that patients do not actively engage with their care teams to discuss their wellbeing. It may be that this lack of engagement arises from a sense of deference, embarrassment, stoicism, or an assumption that the doctor will directly ask about wellbeing (Mimiaga et al., 2007). Conversely, HCPs may assume that

patients will volunteer such concerns without prompting, or avoid subjects which are embarrassing the patient (Verhoeven et al., 2003). Another barrier to effective communication between patients and HCPs may be that increased pressure on resources has led to shorter consultation times, which may not lend themselves to a holistic approach, leading to dissatisfaction among patients (Ogden et al., 2004).

Within my practice, I observed that the process of expressing concerns appeared to be cathartic for patients, which in some cases prevented the need for further referral to other services. In others expressing concerns helped to identify what help was needed, which could then be tailored to meet the patient's requirements. These observations led me to develop a number of national research projects that looked at the effectiveness of communication skills training, breaking bad news and the concept of shared decision making in HIV care.

Due to the evolving area of HIV care within my clinical setting and my changing role within practice, I noticed that the patients that I had supported through very complex and challenging times were increasing. Over a period of time my caseload changed and increased in complexity, and I became referred to as the nurse that 'talked'. With this new title, I noticed an increased referral of very challenging, complicated patients that did not meet the thresholds of mental health services. These patients required a degree of support in order for them to continue to access healthcare, remain engaged in services and adhere to treatment.

In order to provide the care the complex patient required I began enrolling on a variety of different training courses, such as motivational interviewing, Socratic questioning, advance communication courses, mindfulness and cognitive behavioural therapy diploma courses. The courses were extremely beneficial to my

own professional development and enabled me to incorporate new techniques into my clinical practice.

As my caseload increased and the complexities of patients grew, I wondered if I could find another way to manage what was becoming an overwhelming workload and an increase in complex patients. I could not see every patient and be available 24 hours a day, 7 days a week, therefore, alternative ways were needed to support complexities that had arisen in patient care.

During this time Joe was experiencing more frequent hospital admissions; and repeatedly informed me of the care he received from professionals, that appeared to lack an understanding of his needs. I wondered whether sharing my experiences and knowledge with other healthcare professionals would help improve the care Joe received. Unsure how to approach this, but thinking practically, I developed a communication course, for HIV nurses that was designed to improve patient outcome through developing therapeutic communication. Thus, I became familiar with literature related to the importance of communication skills when developing therapeutic relationships.

As my thinking and knowledge base have continued to increase, I began to realize that I had made a lot of theoretical assumptions when developing the communication course. I assumed that the research around communications skills training that had been 'proven' to work in other disease areas would be easily translated to HIV care. I assumed that it was a skills deficit that prevented nurses providing care to patients like Joe, and that improved confidence in this area would correlate with more nurses delivering care that met the complexities that patients experienced. Thus my reading

became more concerned with the therapeutic relationship between the patient and the nurse as a way to elicit patients concerns, as opposed to communication per se.

During the development of my course, I had overlooked how nurses intuitively provided support, what skills they used and how they felt that they had developed skills relating to elicit patients concerns. I don't think I had given a second thought to the unique nature of being a HIV specialist nurse or what this brought to the therapeutic relationship. Reflecting on my own experiences in practice and the complex patients I had established therapeutic relationships with, I wondered how the skills I had been taught to help develop relationships with patients. Reflection also led me to reflect on how I had established relationships with patients with complex needs. Through my reflections, I realized that a non-judgmental style and empathic approach appeared to be fundamental in creating the foundation of the nurse-patient relationship in order to elicit their concerns.

To summarise, these thoughts and observations led me to develop my doctoral research project to explore how HIV nurses elicit concerns. With these thoughts in mind the aims of my study were developed:

- To explore HIV nurses' stories about clinical practice
- To explore the therapeutic relationship that develops between the HIV nurse and patient.
- To analyse nurses' way of being when developing therapeutic relationships
- To explore through the use of stories, situations in which nurses have dealt with the emotions of patients with complex needs.

- To develop a way of thinking which contributes to the existing body of knowledge in relation to therapeutic relationships in HIV care, through the elicitation of patients' concerns.

Before going on to develop a relevant literature review and how it related to my research study, I wanted to further consider some background issues relating to patient care in HIV nursing. Initially, I had felt that my research would identify that HIV care needed to be more psychologically focused. I therefore, began consulting the literature to aid my thinking. Whilst my research touches on the concept of psychological care, and as much as I would have liked it to be neatly packaged to explore this concept further, it appeared that psychological care was only one aspect within my research. Despite this, I still feel it noteworthy to mention psychological care and what this might mean within HIV nursing to aid the understanding of my research.

The prevalence of psychological and psychiatric morbidity amongst people living with HIV (PLHIV) is substantially higher than that of the general population (Bing et al 2001 and Harding et al., 2010), with PLHIV twice as likely to be diagnosed with depression (Ciesta et al 2001). HIV also tends to be concentrated in vulnerable and stigmatised populations, with these populations already at greater risk than the general population, for mental health problems (Petra et al., 2002). Psychological difficulties can also result both from receiving a HIV diagnosis and the challenges of living with the disease (Power et al., 2003).

Until recently, psychological distress remained a topic within clinical practice that healthcare professionals (HCP) failed to talk about with patients. Within HIV care, discussing psychological wellbeing became the proverbial elephant in the room. The psychological standards for the management of PLHIV (British Psychological

Society, 2011) were intended to address this and bring about the creation of services to meet these demands. They advocate that there is a need for communication skills training and suggest a tiered system of psychological support for patients, with nurses playing a central role.

In the psychological guidelines for the management of PLHIV, it is recommended that patients are offered repeat screenings for problems affecting their psychological wellbeing, particularly at relevant trigger points (British Psychological Society et al., 2011). Trigger points may include a broad range of possible factors, such as changes in disease progression, treatment failure, and bereavement or relationship problems.

The standards are reinforced by the government's public health policy, which places equal emphasis on physical and mental health (DH 2011 a). This is also central within the government's ambitious mental health strategy *No Health Without Mental Health* (DH 2011 b), which acknowledged that mental health is central to our quality of life. The report stressed that mental health is everyone's concern, with good mental health and resilience being fundamental to our physical health, relationships, education and training – and in attaining our potential and achieving our goals.

Thinking about the standards of care and how they could be incorporated into patient care, I began to think about what might be required from the nurses in order to deliver the type of care that patients required.

Reflecting on my observations from clinical practice, mental health issues inevitably arise within complex caseloads and in particular, the patients that I provide care for as a specialist nurse. I am often the first to assess the risk of mental distress and observe for signs and symptoms of mental health problems. The vast majority of my

clinical work entails dealing with a complex set of feelings, such as emotional distress, depression and anxiety amongst patients. When I looked at the care that I was providing, rather than it being based predominately on a psychological or medical model, it was more patient centred and reflected the patients' needs. I had the ability to provide support in relation to complex medical information and also support patients with strong emotions. My medical colleagues often belittled my practice and I started to notice that they favoured a more medical approach. This level of criticism led me to wonder how other HIV nurses provided care, how they elicited patients' concerns and how they were responding to the changes in patient needs within their own clinical practice.

With this in mind I began to explore the literature to help guide my thoughts concerning the concepts that I was beginning to formulate and to help shape my thinking further. Thus, at various stages of my doctoral journey, I have familiarised myself with a broad range of literature, some of which I have already cited. I have developed a literature review that encompasses a variety of relevant concepts that assist with the theoretical understanding of my research. Within the next chapter, I will review and discuss the literature that I have drawn on whilst undertaking my research.

Chapter 2: Literature Review

Initially a systematic review was performed using the following terms:

communication, therapeutic relationship, HIV, HIV infection, nurse patient relationships, empathy, patient centred care and nursing. Once the data had been collected and analysed it was clear that this literature review, whilst informative would not illuminate or add value to the findings and analysis. Therefore a decision was made during a supervisory session to search the scholarly literature based on the interpretation of the data from the research itself. The same search strategy was implemented, as new themes emerged from the data analysis to aid interpretation and increase understanding of the emerging themes from within the data. The key search terms that were used to develop the literature review based on emergent themes from the data were, person centred care, person centred nursing, humanistic care, authenticity and HIV nursing. The terms were used singularly at first and then added together to widen the search.

With regards to the literature a broad- brush approach was used when reviewing the literature. The following databases were searched CINAHL, Pubmed, Web of science and Psycinfo using the above identified key terms. Once the journal articles had been identified and selected for suitability a further searching of the journals reference list was undertaken in order to ensure that all the relevant research cited was obtained for primary review. In an attempt to ensure all relevant articles were obtained. Google scholar was also searched and a hand search of specialist journals was undertaken. Key textbooks were also read to assist with the interpretation of the data.

Reviews were carried out to conceptualise person-centred care, stigma and authenticity. It was important to conceptualise what person centred care was in relation to nursing, in order for it to then be translated into HIV care. There was a

need to explore the concept of stigma to add context to the study, as this was felt to be a key issue within HIV care that makes HIV nursing different from generic nursing. When reviewing key concepts it was also important to consider the concept and philosophy of authenticity, as this was a key theme that was beginning to emerge from within the data. The overall choice of literature has emerged from the research. Throughout the doctoral journey the literature review chapter has always been a fluid chapter, which has been continually adapted to reflect emergent themes. The key reports, documents and literature that have driven the literature and interpretation of the data will be discussed within the literature review.

At various stages of the doctorate journey I have familiarised myself with a broad range of literature and a range of theoretical concepts. Initially, it was difficult to decide what to include within the literature review; there were other theories that I could have explored within this literature, so I had to be pragmatic in my thinking otherwise this would have been a very lengthy chapter. Therefore I chose to focus on key pieces of literature and concepts as previously highlighted, that I felt would aid the readers' understanding of my research, analysis and discussion chapters. I will now go on to discuss the literature, which has been presented in a way that builds on key concepts and theories to aid the interpretation of the data.

It was through familiarising myself with the literature at various stages of the doctoral journey, that I observed that there was a wealth of literature available with regards to communication, communication skill training and the negative aspects of caring for PLHIV. However, there appeared to be a gap within the literature concerning the positive aspects of providing care for PLHIV and in particular how nurses use themselves therapeutically, in a positive way, in

order to elicit patients' concerns. The extent of this gap within the literature formed the basis of my research study.

O'Gara and Fairhurst (2004:166-167) have noted that "The Department of Health (DOH) describes a vision for an NHS that is designed around the patient, working continuously to improve the quality of its services. Within these health policy documents, nursing and its contribution to the provision of accessible health care, is a prominent feature (DOH 2014, 2000,1997)".

Nurses are central to the government's health reforms. As a result nursing, as a discipline, has been placed under much pressure to demonstrate its efficacy; in an era of evidence based practice, where nurses are required to provide care that is evidence based, has the patient at the heart of the decision making, and is delivered with compassion (DOH 2014, 2000,1997). A variety of different systems and measures have been utilised to make sure that nursing interventions are evidence based (Freshwater and Stickley 2004,Williams and Stickley 2010).

2.1 Person Centred Healthcare

There have been multiple criticisms of the NHS of late, the most notable being the Mid Staffordshire inquiry. The current criticisms of the healthcare system are that it lacks compassion, with care being delivered in a de-personalized manner (Francis 2013). Miles and Asbridge (2014:135) argue that over the past two decades evidence based medicine has "accelerated the rate of de-personalisation in healthcare by reducing clinical practice to the application of technical procedures and pharmacotherapeutics concentrated solely on the mechanistic treatment of organic disease".

As mentioned within the previous chapter, HIV care has experienced significant medical advances, which enables the medical management of HIV to be more effective. Although there have been great scientific advances in medicine, the psychosocial aspects of the management of the disease have remained stationary, making its management more problematic. Due to these rapid medical changes within HIV, nurses are faced with ensuring that they provide high quality care whilst meeting national tariffs which outline the care that patients should expect to receive. The role of the HIV nurse is changing rapidly in order to meet new service specifications and patients' changing healthcare needs. Within HIV services there has been a move towards the medical management of HIV care, as the disease area has moved into being a long-term condition. This has led to existing models of care being reviewed and adapted to meet patients' needs. Multiple changes in service delivery bring increased concerns that HIV care will lose its patient-centred focus in the face of medical advances and the growing momentum of the evidence base of the disease area.

Person-centred healthcare is based on a philosophy in which humanistic ideals can be implemented into clinical practice alongside continuing scientific advances (Miles, Asbridge, Caballero 2015). Miles and Asbridge (2014:1) suggested that "person-centred healthcare (PCH) is a new way of 'thinking and doing' in clinical practice", a method which has become necessary due to "medicine's relentless empiricism, its positivistic reductionism and its failure to care for patients as individuals". Miles (2011:619) had previously defined PCH as "a humanistic framework of clinical practice which recognises the importance of applying science in a manner which respects the patient as a person and takes full account of his/her values, preferences, aspirations, stories, cultural context, fears, worries, or hopes and which thus recognises and responds to emotional, social and spiritual necessities in addition to physical needs".

The European society for person-centred healthcare discussed two philosophical systems of importance with regards to this area of care (Miles 2011). These are the philosophies of personalism and non-foundationalism, two substantially influential systems of thought that, contribute enormously to the coherence and durability of the philosophical underpinnings of person-centred healthcare (Miles and Ashbridge 2013).

Within person-centred healthcare the patient is viewed as a person with dimensions which extend beyond the purely physical and which includes the psychological, emotional, existential/spiritual and social components of human existence.

Once I had explored the theoretical concepts surrounding person-centred healthcare, I became interested in exploring how these philosophies are implemented within clinical practice from a nursing perspective. I therefore consulted the literature with regards to person-centred nursing.

2.1.1 Patient Centred Care and Nursing

McCarthy (2006) noted that nursing literature frequently refers to concepts such as person or patient centred care/ focused care and individualised care; although there is little empirical research into this form of care. She notes that generally the concept(s) involve “working in partnership with patients to meet the physical, psychological, social, emotional and spiritual needs” of each person (McCarthy 2006:630).

Person-centred care has long been association with nursing. The principles of PCC are understood “as being concerned with: treating people as individuals; respecting

their rights as a person, building mutual trust and understanding and developing therapeutic relationships” (McCormack and McCance 2010:1). Rodgers (1984) wrote about the notion of person-centred care in the early 1940s. He considered that a person centred approach was necessary to enable each persons’ individuals’ qualities to be drawn on, to aid difficulties in their care. McCance et al (1999) linked person centeredness to caring per se, by noting common elements of both such as: relationships, values, caring process and the environment of care (context). Whilst Dewing (2004) noted that the person centred approach occurred through the use of a humanistic caring framework.

Within the literature, PCC has been defined in a variety of ways. The Institute of Medicine (2001:49) defines PCC as “care that is respectful, and responsive to individual patient needs, and values, and ensuring that patients’ values guide their clinical decisions”. McCormack (2003: 203) defines PCC as “the formation of a therapeutic narrative between professional and patient that is built on mutual trust, understanding and sharing of collective knowledge”. Morgan and Yoder (2012:8) uses a combination of these definitions by defining PCC as being a “holistic (biopsychosocial-spiritual) approach to delivering care that is respectful and individualized, allowing negotiation of care and offering choice through a therapeutic relationship where persons are empowered to be involved in decisions at whatever level is desired by that individual receiving care”.

The above definitions go some way to demonstrate what is meant by PCC, by allowing an understanding of the elements involved in its delivery. A central principal of PCC involves the development of a therapeutic relationship that it is based on mutual trust and draws on collective knowledge in order that individuals can be involved in decisions about their own care.

The person-centred nursing framework was developed from other existing frameworks such as McCance et al (2001), McCormack (2001, 2003) and McCance (2003). McCance's framework was developed using both nurses' and patients' perspectives; and McCormack's framework from practice with older people. Through a systematic process of identifying similarities and matching elements across frameworks the key concepts of each of the conceptual frameworks were identified and then merged in order to develop the person-centred nursing framework (McCormack and McCance 2005).

This framework comprises of four constructs:

1. *Prerequisites*, which are dependent on the nurses' ability to know themselves and be clear about their beliefs and values before they are able to help others.
2. *The care environment*, which focuses on the context of care delivery This included appropriate skill mixes effective staff relationships, facilitation of shared decision-making, supportive organisation systems, and the potential to innovate and take risks. It is noted that the care environment is the biggest influential factor on person-centred nursing and the ability for person-centred care to take place.
3. *Person centred process*, which focuses on the way care is delivered. This includes shared decision making through engagement and working with patients' values and beliefs.
4. *Expected outcomes*, which are the result of effective person-centred nursing. This includes satisfaction with care, involvement in care, through the creation of a therapeutic environment. "The person-centred nursing framework provides a basis for benchmarking existing practices and determining changes needed for practice to be based on the principles of person-centeredness" (McCormack and McCance 2006: 478)

Person-centeredness is a principle that goes across different specialties within nursing and is also implicit in a number of nursing models, particularly models of nursing which have a humanistic philosophical underpinning (Watson 1989, Boykin and Schoenhofer 1993, Johns 1994). From the literature, five models have been identified and will be explored. Whilst reviewing the literature there were other models identified that explored the concept of PCC. However, the following five models (Authentic conscious, Positive person work, the sense framework, Skilled companionship, and the Burford nursing development unit) focus explicitly on nursing. These five models have been previously summarised by McCormack (2004).

Authentic conscious, was a model developed for working with older people by McCormack (2001, 2003, 2004) and “is built on the concept of ‘authenticity’ and its meaning in a caring relationship. The framework emphasizes partnership working between nurses and older people based on a ‘negotiated relationship. Five ‘caring duties’, informed flexibility, mutuality, transparency, sympathetic presence and negotiation, direct the relationship between the nurse and patient” (McCormack 2004:35). Within this framework the relationships between nurses and patients are of key importance, with the values of the nurse and patient being significant in shaping the care that is received.

Positive person work was developed by Packer (2003) and draws on Kitwood’s (1997) work within dementia care, termed ‘positive person work’. Packer’s model argues that the person with dementia’s voice should be heard with equal status to the voices of others (professionals and lay person). “The model is built on 12 ‘core elements’ (recognition; negotiation; collaboration; play; stimulation; relaxation;

validation; holding; giving; facilitation; creation and celebration). Packer explores the meaning of these concepts from the perspective of how they might be experienced by the person with dementia. In addition, the care contribution of nurses in enabling these experiences to be realized in practice are described. Relationships, the individual context, the impact of the care setting and notions of self are all considered in the model". (McCormack 2004 :35).

The framework consists of six senses that together account for the intersubjective perceptions of care experiences for both older people and staff. The senses are – a sense of security; a sense of continuity; a sense of belonging; a sense of purpose; a sense of fulfillment and a sense of significance. The framework is intended to account for the subjective experience of ageing and those structural elements that enable or hinder successful care experiences. Knowing the older person and their carers is central to the successful implementation of the model. (McCormack 2004:35).

Titchen (2000, 2001) developed the conceptual framework of 'skilled companionship'. It uses the metaphor of a companion accompanying another on a journey as a carrier for a range of theoretical ideas and symbols. The framework of skilled companionship comprises two domains of knowledge – relationship and rationality- intuitive domains and an overarching domain of 'therapeutic use of self'. Each domain includes processes that are realized through a range of practical strategies. Skilled companions take themselves, as a person, into the relationship with patients and families. Self-awareness, self-knowing, involvement and connection with the patient or family member demands professional artistry in terms of synchronicity, balance, attunement, interplay and perspective transformation. The relationship domain with its concepts of 'mutuality' (working with patients and families), 'reciprocity' (the mutual giving and receiving in the relationship),

'particularity' (knowing the patient as a person) and 'graceful care' (using all aspects of self) emphasizes the importance of the nurse using practical strategies to realize active involvement and choice. (McCormack 2004 :36).

Through on-going practice development exploring therapeutic nursing, the Burford nursing development unit created the BNDU model of nursing. The model is underpinned by a philosophy of humanistic caring and operationalized through an explicit focus on the 'person of the patient'. Key to the model is the assessment process and its core question 'what information do I need to be able to nurse this person?' Nine questions all seek to answer this core question with the intention of building a picture of the person that reflects their biography. Care planning is undertaken with the patient and while it proposes a particular care-planning framework, the essence of the planning process is the negotiation of care inputs that reflect the individual's biography and the relationship between nurse and patient. The reflective practitioner is a central part of the model, as it is through reflection that the nurse evaluates the therapeutic effectiveness of the relationship with the patient. (McCormack 2004:36)

Whilst exploring the theoretical concepts that underpin the models, certain themes recurred across the conceptualisations; knowledge of the person/patient; values of the nurses and patients; authenticity; relationships; going beyond immediate need; and biography.

There is an implicit notion within the models that the nurse needs to move beyond practical competency and engage in humanistic caring, supported by a variety of different knowledge, in order to promote a partnership approach to care which facilitates shared decision making.

It is acknowledged, however, that a key challenge is translating these complex concepts into actual nursing practice. Mutual trust and understanding and sharing collective knowledge through a therapeutic narrative is necessary for person centred practice (McCormack 2003). Therefore, as Morgan and Yoder (2012) note the quality of care provided is strongly influenced by the interpersonal relationship between the nurse and the patient; and the overall health and wellbeing of the patient should be at the centre of this relationship. However, the presence of a therapeutic relationship does not mean that the relationship is patient-centred. Theorists have argued that by using terms such as noncompliance or patient to describe aspects of an interpersonal relationship, the nurse “assumes the authority, power and control (Ingram, 2009, Leplege et al 2007, Slater, 2006). In contrast the practice of PCC creates an interpersonal relationship that shifts the focus from the clinician to the person for whom care is being delivered” Morgan and Yoder (2012:8).

The concept of the therapeutic relationship requires nurses to be held responsible for creating a healing environment through their practice. This practice is thought to be fundamental for care to take place. It is also acknowledged that healing does not have to take place for the relationship to be considered therapeutic. Often patients make choices about the care that they receive which may affect ‘healing’. This choice allows the patient to feel supported as a result of the therapeutic relationship that has been developed (Freshwater and Stickleby 2004).

After exploring the concept of person-centred nursing, I became keen to explore how these concepts were translated into HIV nursing and what were the key issues within HIV that may impact on the delivery of PCC.

2.1.2 Patient Centred Care and HIV Nursing

The way in which nurses provide care to PLHIV has been reported and considered through numerous studies and reviews, not least because the stigma and discrimination this patient group is subjected to, is recognized as a major problem; with PLHIV often perceived as being dangerous and being to blame to some extent for their condition. This stigma can subsequently influence the nurse patient relationship (Hodgson 2006, 2011 Valimaki et al 2008, Rintamaki et al 2007, Vance 2008). The vast majority of the studies reviewed considered care being given to patients by nurses who do not have any experience of working with PLHIV; with little research been carried out to explore the care provided by HIV experienced nurses.

Within the literature, Valimaki et al (1998) and Lohrmann et al (2000) have suggested that attitudes and intentions around care are closely interwoven, although some evidence has also suggested that nurses who have more experience of caring for PLHIV are able to move beyond any potential anxiety they may have in relation to fear of transmission to a better understanding of the patients' healthcare needs (Witt Sherman and Quellette 1999). Knussen and Niven (1999) show that contact or experience of working with PLHIV could affect nurses' perception and their ability to meet patients' needs in a positive way. Healthcare professionals with little or no experience of dealing with PLHIV had more negative attitudes towards patients, which impacted on the care that patients received. The negative attitudes meant that patients did not get the medication they needed or were exposed to HCPs' negative attitudes.

Barbour (1995: 230) suggested that it is "the combination of demands involved" that makes HIV care different from the care of other patients – including stigma and fear of infection. Barbour (1995) also investigated the particular stresses that are faced by nurses providing PCC for PLHIV and concluded by stating that the major source of

stress for nurses in these environments was the negative responses from other people. Subsequently, if support is not present from significant others then the nurses' ability to provide PCC is potentially altered. Hayter (1999) acknowledges the struggles faced by community HIV nurses in relation to high stress levels and the significant risk of burnout. Hayter (1999) also suggests within his study that the demanding nature of such work was balanced by other rewarding aspects of this area of care and the close personal relationships that developed. Witt Sherman (2000) also identified the 'emotional connection' as part and parcel of the HIV nurse's role. Research has also identified that whilst the work in HIV care was more demanding if patients were cared for on dedicated HIV units as opposed to "scattered beds" in a medical unit. Nurses on such units experienced lower levels of emotional exhaustion (Aiken et al 1997).

There appeared to be a lack of published literature in relation to the specific nurse-patient relationship of nurses caring for PLHIV. Hodgson (2006), in his ethnographic study explored how experienced nurses related to those infected by HIV. Hodgson's findings "gave important insights into the culture of HIV care, as constructed by the carers. This was characterized by an egalitarian social structure, significant social distance from other people, and evidence of an alternative moral perspective and close engagement with the client group with confidence in the role of standard (universal) precautions in enhancing safety" Hodgson (2008:285). Within the participants' data extracts there was a strong sense of empathy with non-judgmental attitudes being essential in providing compassionate stigma free care.

Exploring the literature further with regards to how PCC would manifest in HIV care the therapeutic relationship has also been discussed in relation to the role it has on the patients' ability to adhere to antiretroviral therapy. Molassiotis et al.'s, (2007) study of 38 HIV patients in two UK units explored the therapeutic relationship and the

impact that this had on adherence to antiretroviral therapy. The findings suggested that perceiving being valued and respected and the potential to discuss treatment, raised trust in patients and contributed to medication adherence.

Such a relationship has been identified in the general literature with a meta-analysis of 79 studies suggesting that the effect of the therapeutic relationship on medical outcomes was seen to have a moderate but consistent correlation (Martin et al 2000). Although the importance of the therapeutic relationship has been highlighted as being significant to a patients' outcomes on treatment, the characteristics of the therapeutic relationship has remained un-documented within the literature in general. Within the HIV discourse the focus of the therapeutic relationship has been to encourage patients to adhere to treatment.

Throughout the literature when exploring the therapeutic relationship in HIV nursing the theme of stigma became a dominant one and an important element in the nurse's ability to provide PCC. The awareness of the impact of stigma seemed to be a unique aspect of the HIV nurse's role in providing care for the patient.

Since the beginning of the epidemic in the 1980s, people living with HIV have experienced stigma and discrimination. Stigma is considered the second pandemic of the HIV virus (Hodgson et al 2012). The prevalence of stigma concerning HIV has led, to numerous attempts to try and reduce HIV related stigma. Sadly, these efforts have had very little effect, as the general public still have very strong misperceptions about HIV (Hodgson et al 2012).

Since the earliest identification of HIV cases in the early 80s the virus had been referred to as the 'gay plague' (Shilts 1987). Sontag (1998) proposed that the term 'plague' suggested that the illness had been inflicted upon people, possibly as a

punishment from God. The concept that HIV is a punishment from God goes beyond religion and continues to facilitate discrimination whilst hindering attempts to prevent the spread of the disease (Adebajo, Bamgbala and Oyedrain 2003, Hess and McKinney 2007).

The association HIV has with gay men has potentially led to some negative societal and cultural attitudes towards homosexuality being transferred onto HIV as a disease, so that it is associated with deviant/immoral behaviour (Sowell and Phillips 2010). HIV has also been identified with other subgroups of society, such as intravenous drug users, prostitutes, ethnic and racial minorities. This further enforces negative perceptions of the disease, which is often associated with immorality and deviations from social norms, and the 'others'.

The stereotyping of PLHIV as being responsible for their disease and thus unworthy (Balabanova et al 2006) can be very powerful and pervasive for the individual resulting in them internalizing negative feelings and stereotyping resulting in feelings of being unworthy and shame (Goffman 1963, Jones et al 1984).

Hodgson (2007: 5) stated that "Stigma is an attribute that discredits a person, denies full social inclusion and draws on arbitrary rules of inclusion and exclusion" and that "discourse around (HIV) stigma has focused less on stigma as a phenomenon in itself, but rather on it as a result of underlying processes".

Mburu et al. (2013:1) stated "there is a wide body of literature exploring HIV stigma, which is now recognized as a complex multidimensional phenomenon (Mahajan et al 2008, Deacon et al 2005, Sengupta et al 2011)". Deacon et al (2005: 19) identified core elements of HIV stigma when they proposed that HIV stigma is "an ideology that claims that people with a specific disease are different from 'normal' society", as well

as a “ social process by which people use shared social representations to distance themselves from the risk of contracting a disease”. An exploration of this social process shows that HIV stigma is often influenced by the contribution an individual makes to society, that is, whether he or she is regarded as a drain on communal resources (Castro et al 2005, Reidpath et al 2005)” Muburu et al. (2013).

The term stigma was used in ancient Greece to signify physical signs or markings on a person, the represented shame or disgrace (Sowell and Phillips 2010). This physical stigmatization could be seen in the early days of the HIV epidemic, where people looked cachectic from HIV wasting or had lesions of Kaposi’s sarcoma on their faces/bodies. During this era stigma was heightened and the same impact continues with patients today who access care, [who](#) express concerns that people will be able to tell that they have HIV, just by looking at them.

The “negative response to individuals who are deemed different and unworthy remains a reality that transcends cultures and can be observed globally. The act of stigmatizing not only allows the discrediting and devaluing of an individual or group, but also provides the basis for behaviors and actions toward stigmatized individuals or groups that would otherwise be unacceptable. The major focus of the stigmatizer is to assign blame to the individual or group being stigmatized. In this way stigma becomes the responsibility of the individual or group possessing the stigmatizing attribute and this blame supports the concept of punishment (Laryea and Gien 1993)” cited in Sowell and Phillips (2010:395).

Sowell and Phillips (2010:394) also noted that PLHIV are “routinely subjected to fear, rejection, ostracism, hostility and threat of physical and economic violence (Jefferies et al 2015, Balabanova et al 2006, Cao et al 2006, McNeil 1998, Sowell, et al., 1997)”. Thus there is potentially a perceived need by PLHIV to keep their HIV status

secret which may result in negative outcomes both psychologically and physically. Sowell and Phillips (2010) suggested that the frequent interactions that nurses have with PLHIV enables them to help such people develop positive coping strategies to deal with the stigma and psychological challenges of living with HIV.

The literature concerning PCC and HIV, suggests that within HIV nursing, PCC needs to encompass and be mindful of the concepts of stigma.

Initially, I consulted the literature on PCC as I thought that the care participants were describing within their interviews was based around this philosophical concept. Whilst PCC went some way to describe the care that was being delivered, I felt that there was something else that was occurring within the therapeutic relationships that superseded the nurses' ability to provide PCC. This was the nurses' ability to 'be' with the patient in order to provide care. With these thoughts in mind, I consulted the work of Heidegger to understand the concept of being and authenticity further.

2.2 The Concept of Being

Another researcher, who had used Heidegger within their research, suggested that I read his philosophy in order to explore the concept of being. Despite my research methodology, IPA being heavily influenced by Heidegger, I had avoided reading his work as I was daunted by the language he used to explain his theories. Heidegger's peculiar language which has been described as strange and impenetrable (Steiner, 1989) and may put off some readers (Dreyfus 1994)

Putting my concerns to one side, I made a decision to read Heidegger's work as I was convinced the effort involved in understanding his theories would benefit my research. I immersed myself in his theoretical thoughts and began reading

Heidegger's work alongside listening to lectures about the 'great philosopher'. Once I began to understand the tricky language Heidegger used, I quickly began to understand how his work could help illuminate my findings.

I have provided an overview of Heidegger's work within the methodology section and would like to now focus on some of his key theories and my understanding of those in relation to my research. I will focus on *Dasein*, temporality and authenticity when discussing Heidegger's work.

In an effort to understand what it is to be in the world Heidegger's philosophy (1926/62) explores the concepts of both 'being' and 'time' (Collins and Selina 1998: 45). Heidegger's philosophy also considers the temporality of the human being (Dreyfus, 1994) and seeks to understand "experience within the context of everyday lives" (Draucker, 1999:371). For Heidegger *Dasein* is a "way of referring both to the human being and to the type of being that humans have. It comes from the verb *dasein*, which means 'to exist,' or, 'to be there, to be here'"(Inwood 1997:22).

Dasein provides an understanding of being, by exploring the question 'what is being?' and then attempting to answer that question. Inwood (1997: 21) suggests "all human beings, even those who do not ask this question, have some understanding of being, otherwise they could not engage with other beings, even themselves".

A key assumption with regards to *Dasein* is that the person and [worlds](#) are united. *Dasein* does not just occupy a space within the world but engages continually with the world and, through these engagements with the world, evolves and adapts. For Heidegger *Dasein* is a starting point to enquiry. "Heidegger does not focus on one type of entity to the exclusion of others rather, *Dasein* brings the whole world along with it" (Inwood 1997: 22). Thus the concept of *dasein* represents a 'possibility of

many ways of being' (Heidegger 1926/1962: 68).

After exploring how Heidegger's philosophy on being could illuminate my research I became keen to explore Heidegger's thoughts on temporality and historicity, with regards to HIV and the nature of being, which would inform the interpretation of my research.

According to Inwood (1997:11) *Dasein* is "bound up with Temporality" and 'being' cannot be considered separate from time. The term 'Historicity' is used by Heidegger to explore how *Dasein* is related to time; and *Dasein* 'is' its past in the way of its own being, which I have interpreted as a nurse's past affecting their way of being in the present and future. This interpretation links to the idea that *Dasein* links with the past, the present and the future; and so, "has its being in all three temporalities: its past, its possible futures and its present" (Collins and Selina, 1998: 79). Reading this reminded me of how the HIV nurse delivers care, the historical nature of HIV disease and how providing care over the years has changed, from needing to provide palliative care to supporting patients with a long term health condition. The nurse's being is tied up with their experience of nursing PLHIV and their views concerning HIV before becoming a nurse. There is also the historicity that comes with HIV nurses providing care for patients over many years. Looking after patients in the present, whilst keeping an eye on their future care. Therefore, historicity is crucial to our understanding of being (*Dasein*) as it looks both forwards and backwards as well as being in the present.

When considering Heidegger's work in relation to my research findings, and how nurses can 'be' with patients, the concept of leaping in and leaping ahead caught my attention. Within 'Being and Time' Heidegger lays out the idea that there are two distinct ways of caring for others. Heidegger termed these contrasting ways of

helping other people as 'leaping in' or 'leaping ahead'. With 'leaping in', one cares for the other by simply taking up the other's burden and giving it back to him as a finished project. For example, my daughter is struggling with her homework, I tell her all the answers, she hands it in, and she gets an A. On the other hand, in 'leaping ahead' you help the other to take up their own burden by giving them a way to bear the burden in themselves. Using the same example, instead of simply giving my daughter the answers to her homework, I could spend time explaining the actual concept she is struggling to understand. In both situations the outcome is the same; my daughter completes her homework and gets an A (assuming I have adequately taught her the concept). The difference between the two scenarios is that while 'leaping in' and giving my daughter the answers helped her in the short term, it failed to provide the same long-term benefit of 'leaping ahead', in teaching her the concepts themselves.

Similarly this concept can relate to how, as a nurse, I might provide care. I could provide care when a patient comes to me with concerns in a 'leaping in' manner and take over the patient's concerns and 'fix' the issues. Alternatively, I could facilitate a 'leaping ahead' style by working with the patient on their concerns and spending time giving them the skills to enable them to work through their own problems.

2.3 The Concept of Authenticity in the Nurse Patient Relationship

Whilst reading Heidegger's work I came across the concept of authenticity which then led me to deepen my understanding of how nurses develop their own way of being. I began to explore the philosophical concept of authenticity further. The concept of authenticity was mentioned within the literature as being an important component of a therapeutic relationship. I became keen to explore this further in order to understanding how a HIV nurse provides PCC. The more I learnt about this

philosophical concept the more I began to acknowledge its importance in understanding different ways of being. The theme of authenticity appeared to be central to understanding different ways of being. Therefore I felt it was important to share my interpretations of the literature on authenticity with regards to definition, its theoretical perspectives and relevance to nursing practice.

Heidegger was the first of number of existential philosophers to talk about the term authenticity, in any depth (Thompson, 2005). Heidegger considered authenticity to involve critical participation in life. "Those who participated in critical assessment of their lives did not always follow the crowd, as following the crowd would mean they were inauthentic. Heidegger believed that humans were essentially authentic when they chose to be true to themselves and risk being different. Authenticity requires individuals to consider how they want to live and then have their values, attitudes, motivations, and life plans reflect this consideration (Faden and Beauchamp, 1986). An authentic existence, according to Corey (1982), has three characteristics: being fully aware of the present moment, choosing how to live one's life in the moment and taking responsibility for their choice" Starr (2008:56).

Heidegger (1926/62) noted that *Dasein* can either be authentic or inauthentic (Collins and Selina, 1998). To be authentic involves being true to one's self (to be authentic to one's own beliefs); or conversely *Dasein* can conform to the beliefs of others, (the 'they') (Heidegger, 1926/62; Inwood, 1997). Thus *Dasein* can either choose to be authentic to itself or if 'fearing about others' can choose inauthenticity (not be itself) (Heidegger, 1926/62: 181).

Inauthenticity or leading of an inauthentic life is not, according to Inwood (1997:25) an 'unqualified blemish'. He suggested that in order to function within society, we all have to act inauthentically at times and this maybe the "normal condition" Inwood

(1997:25). Additionally Barnett (2007) suggested that authenticity is difficult to accomplish. Heidegger suggested, however, that whilst in an inauthentic state there is a “call to conscience” leading *Dasein* to return to an authentic state; which can be a state causing anxiety and stress Inwood (1997:25)

With this in mind I turned to the scholarly literature to explore the concept of authenticity further, as I wanted to learn more about how these theories could assist in my exploration of the therapeutic relationship in relation to my research findings.

Aranda and Street’s (1999) research explored the contradictory understandings of the interactions between nurse and patient. In their research, concepts of being authentic and being a chameleon emerged. Aranda and Street (1999) argue that the nurse patient-relationship develops with the nurses and patients choosing to either reveal or conceal parts of themselves as they interact. Such interaction being dependant upon intersubjectivity; with the idea that nurse- patient relationships are mutually constructed. The nurses used the word ‘chameleon’ to describe practice which enables them to become the type of nurse the patient required. I consider this in relation to Heidegger’s theory that *Dasein* can choose to be authentic and being inauthentic can serve as a purpose in order to fit in and conform with others, in the discussion section. I consider whether this aspect of Heidegger’s theory could be considered to be the same as being a chameleon.

Guignon (2004:4) stated that social existence often requires us not to be ourselves, as society works best “by making people into cogs in the machinery of everyday life. The outer-world of practical affairs runs most smoothly when people identify with their roles and fulfil their functions without questioning”. Sartre (1956:59) noted the following about tradespeople: “The public demands of them that they realize (their occupations) as a ceremony: there is the dance of the grocer, of the tailor, of the

auctioneer by which they endeavour to persuade their clientele that they are nothing but a grocer, an auctioneer, a tailor. A grocer who dreams of other things, is offensive to the buyer, because such a grocer is not wholly a grocer". This is because social pressures act to move us toward inauthentic role-playing. As such being authentic takes significant effort.

Starr, (2008) described authenticity as the internal motivation to be true to being (personality, character and spirit) in the way they relate to the world. This can lead to a life which runs counter to cultural norms and requires consideration of what is true to the self.

Baykin and Schoenhofer (2001:14) describe authenticity and its relevance to nursing in the following way, authentic "presence may be understood simply as one's; intentionally being there with another in the fullness of one's personhood. Caring communication through authentic presence is the initiating and sustaining medium of nursing within the nursing situation".

Thompson (2005) explored the concept of authenticity from a psychological perspective and suggested authenticity is about taking a more difficult path. Such a path that is in the end, more genuine and more rewarding than an easier path influenced by other. Suffering may result from searching for authenticity, as anxiety may result, linked to revealing their true selves and living with the consequences of such choices.

From the literature it can be suggested that for nursing authenticity involves both participants within the nurse-patient relationship; and is necessary for the development of a trusting relationship (Falk- Rafael, 2001). Radwin (2000) suggested that authenticity can be promoted by quality nursing care, which then creates a

sense of well-being; and that authenticity is appreciated by patients. Within Radwin's research, patients describe authenticity as having the 'freedom to be themselves' revealing warts and all and that "patients did not feel the need to put up a façade while maintaining their self-respect and pride" (Radwin, 2000:183).

After reading the various definitions and explanations of what authenticity meant, I began to reflect on my own practice in order to understand what authenticity meant to me. I could relate to Heidegger's philosophy and considered that in order to be authentic within the therapeutic relationship, I needed to be present and aware of my own beliefs and values in order to be with someone. Being present with someone and supporting them with their needs were important aspects of being authentic to me. I also considered the concept of being inauthentic and how at times I had been inauthentic when providing care. I consider my practice to be both authentic and inauthentic and can relate to the research undertaken by Aranda and Street (1999) who talk about the chameleon nature of nursing.

After many hours of reflection I came to the conclusion that when I refer to being authentic, what I mean is the ability to be present with someone and aware of any beliefs or values that may affect my ability to be with someone. I also consider being authentic as having the ability to create a therapeutic relationship that allows for both participants to develop, based on mutual trust.

In summary, I consulted the literature in order to explore the concept of PCC, and a variety of different definitions were explored in order to establish what this concept meant. Once I had established a working understanding of PCC I then turned to the literature in order to explore this concept in relation to nursing. The literature pertaining to HIV nursing highlighted that there was little research carried out in relation to how experienced HIV nurses provide PCC, especially specialist HIV

nurses. There appeared to be a focus on how inexperienced general nurses provided care for PLHIV. What appeared to be significant in relation to PCC and HIV nursing was, with regards to patient outcomes, the positive effect therapeutic relationships had on adherence to treatment.

Heidegger's philosophy was explored, particularly his thoughts on *Dasien*, temporality, historicity, caring and authenticity. Through reading Heidegger's work a way of being was identified as being a lens in which PCC in HIV nursing could be explored. Authenticity appeared to be a key component in providing PCC which led to the discourse on authenticity being explored. This helped to consolidate my own understanding and thoughts on authenticity and in doing so has shaped my interpretative lens.

Chapter 3: Methodology

3.1 Epistemological Position

Prior to undertaking my research I felt that it was important to identify my epistemological position in order to help guide my thinking about my methodology. It has been highlighted by Ballinger (2004) that a researcher makes their epistemological position clear within the research design. I therefore felt that it was important to spend some time reflecting on my epistemological position in order to understand how I considered knowledge should be generated as a result of carrying out my research. Gray (2005) suggested that epistemology is concerned with identifying what knowledge is considered to be valued, true and accepted as real.

Willig, (2008) suggests that a researcher's epistemological position influences the approach to research that is taken. Whilst making sense of epistemological positions I began to view these positions as forming a tree, with the main epistemological positions making up the trunk and the branches making up the various sub-positions that emerge. If at the base of the tree was a realist or positivist position, metaphorically forming the roots of thinking, I would, as a researcher, adopt a quantitative approach utilising methods in order to discover perceived truths or reality. It is considered that the positivist epistemology is concerned with developing research which will produce objective knowledge, in particular knowledge which is unbiased and which takes a view from 'the outside' with no personal involvement from the researcher.

Thinking about my own research and life, I soon realized that this was not a stance that I could adopt. I have been a HIV nurse for 20 years and so much of who I am is tied up in that identity. As such the HIV nursing world is a world that I am very much embedded in. Therefore I did not believe that I would not be able to view things from the 'outside'.

All paradigms can be characterized by the way their proponents respond to three basic questions. What is the nature of 'reality' (Ontology)? What is the nature between the knower and the known? (Epistemology) and how should the enquirer find knowledge? (Methodology) see Giddings, (2006) Guba (1990). Through a process of reflexivity, I checked my personal beliefs concerning the research process were alongside my ontological assumptions, epistemological perspective, and the axiological assumptions and methodological perspectives I held. I studied the literature looking at a range of philosophies of research before reaching the conclusion that the pragmatist worldview best met my underlying beliefs about how the process of research should take place.

Pragmatism's worldview is concerned with finding middle ground rejecting the 'either or choice' between constructivism and post positivism (Guba, 1990; Morgan, 2007). Pragmatists are concerned with solutions to problems and the notion of what works with regards to undertaking research. Pragmatists will use a variety of different approaches that are available to them in order to understand the problem under investigation. When developing research, pragmatists will explore the intended outcomes of the research in order to direct the way in which they will achieve these objectives. Therefore utilising this approach to research would involve being outcome focused, which then drives the research design. Pragmatists also believe that research is carried out in a variety of different contexts which also influences outcomes, some of these contexts being social, historical and political in nature (Creswell 2012).

After careful consideration I realised as a result of my exposure to different research methodologies, that there are different ways of viewing how and why things happen, with many different ways to investigate how and why things occur. Prior to undertaking my doctoral research I had been involved in two national research

projects that utilised a mixed methods approach. As a result of engaging in this research I began to understand how both subjective and objective information could be used to explore the research question. Using the methods which appear to be best suited to the research problem, and having the freedom to use a variety of different techniques in order to explore the research question, is in line with a pragmatic approach (Crewsell 2003). This view eventually influenced the research design of my doctoral studies as I began to explore pragmatic philosophy.

The research question that I had identified, ('How do HIV nurses elicit patients' concerns?') was interpretative in nature, as it sought to explore nurses' experience of eliciting patient's concerns. Identifying the question early in the research process is important from a pragmatic perspective, as the question will influence the design of the research, rather than letting the research design influence the question(s) (Tashakkori and Teedlie 1998). Therefore a pragmatic approach required me to address the research question in a way that I felt answered the question, which in turn moved me towards addressing the research aims.

Exploring the pragmatic approach further with regards to how it could assist with my research design, a pragmatic philosophy involves understanding how knowledge is developed and emphasises the researchers' role in this development. "The researcher is participating in practice in order to explore – through personal actions or close observations of others' actions the effects and success of different tactics" (Goldkuhl 2012:141). The main themes of pragmatic research is that thoughts and practices should be considered in relation to the usefulness and practicality of the research, and that this would highlight the level of value to the individual practitioner, patient and researcher (Goldkuhl 2012).

After reading through this and exploring the types of knowledge that made up my own specialist base, I felt that a pragmatic philosophy paradigm was a good reflection on how I practiced nursing, seeking to find solutions which were firmly based in gathering evidence, which best fits the perceived problem, whilst realizing the diverse complexity of HIV and the context in which it occurs. McCready (2010:192) reinforces this when exploring nursing practice, stating that “simply and plainly nurses want to do what works and they do and think about what they do in terms of effectiveness/usefulness in meeting practical goals”. Thus McCready aligns aspects of nursing practice with pragmatism. From this research I considered myself as taking a pragmatist perspective, as I believe that this approach is instrumental in leading change in practice, as a pragmatic approach can create knowledge that is useful for practice.

When reading around pragmatism John Dewey's theories came to the forefront. One of Dewey's theories particularly resonated with me, which was the idea that all human inquiry is itself tied to experience and that all knowledge should be considered as hypotheses to be tested in experience (Dewey 1929/1958, Kloppenberg 1996). With this in mind I considered my patient consultations, particularly, giving a positive HIV diagnosis. Each experience is different for each patient. As professionals we have knowledge of what this may mean for people, but fundamentally this will be different for different patients and very much linked to their previous experiences and to, social, and psychological context. This links to one of Dewey's main areas of thinking in regards to what happens after the action has taken place. Using the example of giving a positive HIV diagnosis, the consequence of the action is what gives it meaning. The consequences of giving a positive HIV diagnosis could be very different for different people, which will invariably alter the meaning for them. For example, if the diagnosis results in the loss of a relationship, this will

impact on the patient differently to if the diagnosis results in preventing onwards transmission to a loved one or unborn baby.

Pragmatism directs the research to focus on the practical consequences of ideas, theories and actions. Therefore, I believe my research question, ('How do HIV nurses elicit patient concerns') is a pragmatic one.

Once I had established my pragmatic position, I turned my attention to the way in which I wished to generate knowledge within my research. When I first began thinking about my research I explored a variety of different methodologies in order to find a suitable approach that I could use to carry out my study. I was encouraged to spend lots of time reading around a variety of different research approaches in order to use them to guide my doctoral studies. After a while I started to feel overwhelmed by the complex terminology and the very tricky philosophy that underpinned certain approaches to research. I was encouraged to find a methodology that gave me 'an inner smile' (Brewer and Hunter 2006:13), one that was similar to my beliefs as a person and a practitioner. I wondered for a long time what all this advice meant, after much thinking I arrived at the following conclusion.

Essentially, as HIV nurses, we are often required to provide care in a way that facilitates a patient's ability to make sense of what is happening to them, and what HIV means to them, both individually and within society as a means of helping them adjust to their HIV diagnosis. As a nurse I am involved in helping the patient make sense of the HIV diagnosis, drawing on my own mental facilities in order to help patients make sense of their experience.

In order to choose a methodology for my research I spent a considerable amount of time in the library reading research that had not been carried out within in my

discipline, so that I could focus on the research process that they had undertaken in order to establish if this was an approach to research that would fit with my research aims. I also obtained book length versions, where possible, of the studies that I found particularly interesting in order to get a more in-depth idea of whether using this approach would help me with my own research study. During this process I looked at ethnography as a possibility but excluded this as an approach as I felt my presence would alter the dynamics within the therapeutic relationship that I was trying to gain insight into (Hammersley and Atkinson 2007). I excluded Grounded theory on the basis that I did not enjoy reading the book length versions of the studies that I obtained and felt that this methodology would therefore not give me the drive I needed within my own work it also seemed that these studies took several years to complete (Urquhart 2012). Therefore, based on my pragmatic epistemology I thought that a phenomenological approach, such as IPA, would enable me to explore the lived experiences of the participants and afford me the opportunity to capture the thoughts and feelings of my participants more than the other two approaches of ethnography and grounded theory that I had explored as a potential methodological approach.

After many hours of reading I was advised to bring to my supervisor session exemplar texts of studies that I had read and enjoyed. With this in mind I consulted the literature in order to look for a research methodology that would enable me to explore this phenomenon. As a consequence I began reading about phenomenology and began to realise my research would seek to understand the thoughts, feelings and experiences of HIV nurses, therefore a phenomenological approach to my methodology felt appropriate. After exploring different phenomenological approaches I began to focus on Interpretative Phenomenological Analysis (IPA) which seemed to be used by others when exploring psychological aspects of various phenomena (Eatough and Smith 2006, Bromley and Eatough

2005, Robinson 2002). IPA seemed to be the most appropriate choice of methodology to enable me to reach my research aims. I had enjoyed reading the book length versions and thesis that I had obtained and became keen to explore this methodology within the context of HIV nursing care.

Initially what attracted me to IPA was its idiographic stance (Eatough and Smith 2006, Bramley and Eatough 2005, Robinson 2002) which will be explored in more depth within this chapter. The idea individual narratives that were then compared to the other participants idiographic accounts in order to illuminate shared themes. As my research began to unfold it was clear that I needed to use a pragmatic approach as I wanted to use the collective narratives to develop a theoretical framework that would meet my research objectives of how HIV nurses elicit patients' concerns. The idea of developing a model was to some extent incongruent with the idiographic stance of IPA that had originally appealed to me when starting my research. However, returning to my underpinning pragmatic epistemology enabled me to reconcile this apparent incongruence with the need to develop an outcome that will be used in practice.

3.2 What is Interpretative Phenomenological Analysis (IPA)?

Interpretive Phenomenological Analysis (IPA) is an approach to qualitative, experiential and psychological research. This approach is still open to much debate in relation to its origins and differences to generic qualitative research. Smith developed this theory in 1996 as an approach to qualitative enquiry. In psychology, IPA has been adopted across a range of different applied psychologies, such as health, counselling and nursing. Over the past 20 years IPA has grown in popularity and continues to gather momentum as an approach to experiential research (Smith 2011). The approach recognises the role of the researcher in interpreting and then understanding the experiences of the participants, offering a stance from which to

interpret data generated as a result of carrying out the research. It seemed fitting to explore the origins of this approach to further understand the chosen research design. Three key areas of philosophy and knowledge that have informed IPA are phenomenology, hermeneutics and ideography.

3.2.1 Phenomenology and IPA

Croft (1996) has suggested that phenomenological approaches enable experiences to be expressed in the context of a person's relationship to the world, and therefore enables the creation of a better understanding of the person's experiences to be formulated. This gives greater understanding of how people give meaning to their experiences. Historically, phenomenology is often understood to have two important phases; a descriptive transcendental phase, and a hermeneutic existential phase (Inwood 1997). The phases relate to two separate approaches to phenomenology. Within my research I have focused on the second phase of phenomenology-the hermeneutic existential phase. In order to reach the conclusion that hermeneutic phenomenology would better lend itself to the interpretation of my research, I explored the work of Husserl, with regards to the adoption of the phenomenological attitude and how I might adopt this within my research design. I will therefore discuss Husserl's work with specific reference to his thoughts on the epoché and how these influenced my research.

Within Husserlian phenomenology the adoption of the phenomenological attitude is essential when undertaking research. The adoption of a phenomenological attitude has been referred to by Husserl as a 'natural attitude'. This natural attitude involves bracketing off previous knowledge. This means acknowledging previous knowledge and not engaging with this knowledge during the process of data collection or subsequent analysis. Husserl acknowledges that this is a difficult task that might

involve careful consideration in order to be able to undertake the epoché and, in doing so, suspend previous knowledge. Husserl believed that this process was possible and was very similar to the process involved in setting aside any previous attitudes or prejudices in order to reach an understanding of the information that is being presented in an impartial way.

The second stage involved in adopting the phenomenological or natural attitude involves having the ability to capture the essence or the object (or subject under investigation). Husserl referred to this as being 'free imagination variation'. Husserl used this phrase to encourage alternative ways of thinking with regards to considering different possibilities or circumstances in which the object being studied might be encountered.

Central to Husserl's phenomenological method and perhaps the most important aspect of his theory is the concept of epoché. Several problems emerged in relation to the epoché, which forced Husserl to develop and continuously redefine the concept.

3.2.2 Epoché – My Thoughts and Understandings

Langridge (2007:35) suggested that the epoché is the process used to attempt to abstain from our pre suppositions, those pre-conceived ideas that might be held about the things being investigated.

Reading this I am not sure how easy this will be, as I am not sure if I can suspend my pre-assumptions or ideas. I feel that too much of myself is linked to being a HIV nurse. I consider this to be my way of being, my authentic self. I am not sure I can easily separate my presuppositions or myself, from being a HIV nurse. I became

concerned as to how my inability to adopt the epoché would impact on my research project. I was unsure if this inability would be a positive or negative factor concerning my research. I turned to the scholarly literature in an attempt to understand fully what was meant by epoché and what benefits it would afford.

The epoché might be understood as idealist, as it aim appears to disconnect us from our involvement in the world, allowing us to see the phenomenon 'objectively'.

Through the epoché, we attempt to disentangle ourselves from the world momentarily, without letting go of it, so as to find the 'elbow room to see what is happening when we understand phenomena and meanings' (Dahlberg 2006:16). In this way we can encounter the world anew, with a curiosity and freshness that was not possible beforehand (Giorgi, 1997).

I was keen to learn how I could adopt the epoché within my research. Although I was beginning to learn there were neither prescriptive methods available when utilising a phenomenological methodology nor instructions on how to adopt the epoché.

Nevertheless I began to explore how other researchers had adopted the epoché within their phenomenological research in order to establish how I might utilise this approach within my work (Wall et al 2004). In order to achieve the epoché, Wall kept a reflexive diary. The diary acted as a structure for her to start thinking about her thoughts, assumptions and prior knowledge. Wall et al (2004) used these diary entries to explore what learning had taken place as a result of engaging in this process. Wall et al (2004) considered this process to be about providing a psychological orientation as opposed to a set of procedures to follow. In other words, this process was more akin to a state of mind, reached and maintained throughout the research process.

Rose (1990:59) explained how at the start of her study “personal and theoretical assumptions” were put to one side in writing. Rose does not give the reader any detailed insight into how she achieved this complex process or whether these thoughts crept into the research process or were used as new learning (in contrast to Wall et al 2004). Rose merely stated that her assumptions were written down.

Despite being swayed by what I was reading in relation to this philosophical concept, I was concerned about my ability to achieve this desired state. In an attempt to consider the epoché and my chosen research design (IPA). I returned to Smith, Flowers and Larkin’s (2009) textbook to try and understand how I could incorporate the epoché within my study. Smith, Flowers and Larkin (2009) did not give any definitive answers with regards to the epoché and how it could be used within an IPA study, they merely mentioned the concept with regards to the work of Husserl. The more I read about the epoché the more it seemed like the quest for the holy grail and something that I would not be able to achieve, due to my identity as a HIV nurse being very much part of who I am. Even whilst reading the benefits and apparent ease of being able to achieve this, I still remained unconvinced that it would be desirable or achievable. I was concerned that by disconnecting myself from the study and adopting the epoché, I would not reach a deeper understanding of the phenomena.

Paley (1997:67) also acknowledges the difficult process of bracketing off as part of the research process for the nurse. Paley states that it would be impossible for any social scientist to use the epoché as a research technique, as performing the process would disconnect them from their social world. The researcher’s lived experiences, used as part of the meaning making process would also be inaccessible for the researcher, as they would be unable to use them as a result of adopting the epoché.

Reading this reaffirmed my beliefs that using the epoché would not be possible for me to achieve, as so much of who I am is interwoven into being a HIV nurse. I was unsure how I would separate my knowledge of what being a HIV nurse meant, and, if separated, I could not guarantee that this would not creep into the research process to inform my understanding of the data. After reaching this conclusion I turned to the second phase of phenomenology to establish if this approach was more in line with my worldview.

3.2.3 Hermeneutic Existential Phase

Heidegger

Martin Heidegger (1889-1976) is considered instrumental in the development of hermeneutic phenomenology. Heidegger's work was heavily influenced by the work of Husserl, and Heidegger spent many years studying under Husserl's tuition. Heidegger pushed the boundaries of Husserl's concept of intentionality by theorising that it would not be possible to separate the person from the world. Subsequently, the idea of the inability to separate oneself from the world formed the basis of Heidegger's thinking. Heidegger called this *Dasein*, which roughly translates to being in the world. Heidegger believed that we are not just merely subjects or objects, but that we are what we do. Our actions therefore give us our identity.

One of the main differences in hermeneutic approaches was the recognition that the researcher is part of the research process. In hermeneutic phenomenological approaches to research, the researcher is recognised as an essential part of the research process. Unlike Husserl's descriptive transcendental phenomenology, the researcher is actively encouraged to make use of their pre-assumptions and foreknowledge when gathering data and subsequently making sense of that data. In

order to assist with this process I have stated my pre-assumptions towards the end of the chapter. Our pre-reflective ways of being help form the basis of how we understand and make sense of the world. It is because of this way of being that Heidegger suggests that we cannot separate ourselves from the world or look at objects in a detached way. Heidegger's philosophy played an important part in the development of IPA (Smith 2008). In particular the interpretative aspect of IPA is heavily influenced by the concept of *Dasein*. The impossibility of being able to or even wanting to separate an individual from the world in order to understand their experiences is a central conceptual understanding within the interpretative activity of IPA. Heidegger firmly believed that people are rooted within their historical and cultural worlds. Heidegger also identified other aspects which he referred to as 'facticity' which he believed were unalterable. Therefore to study the world and objects within the world it is necessary to engage with the experience of individuals and the meanings they give to these experiences. Heidegger suggests the researcher is embedded within their own world, as are their research participants sharing the same world researchers and participants co-construct the research process.

Smith (2009) suggests that identifying our fore-understandings enables a more productive form of bracketing. This is a complex and dynamic process and should be viewed as a cyclical process which can only be partially achieved by the research, and will continue to alter the more the researcher engages within the research process. Smith (2010) further suggests that this helps to connect bracketing with reflexive practices, enabling the researcher to develop a phenomenological attitude to facilitate data analysis.

This appeared to reinforce my choice of methodology. As I began to read more of Heidegger's philosophical view, I started to relate more to his way of thinking and felt

that Heidegger's views were more in line with my own ontological perspective. Heidegger suggests our 'being' is context bound. To try and disentangle ourselves from the world would be problematic and would mean analysis would take place out of context. I did not feel that I would be able to 'bracket' off the part of me which was a HIV nurse and then not engage with this part of me when researching HIV nurses. I felt Heidegger, therefore, offered a way of approaching my research through his philosophical views, in particular *Dasein*.

3.2.4 Hermeneutic Circle

A central focus of phenomenological approaches to research, is the hermeneutic circle. The hermeneutic circle is said to represent understanding the phenomena by "connecting with the world as opposed to conceptualising it" (Drauker 1999:27).

The main focus of the hermeneutic circle is to understand the relationship between the parts and the whole. When looking at the parts it is useful to look at the whole and when looking at the whole it is good to understand the parts. In order to conceptualise the hermeneutic circle further, Smith (2007, 2009) suggested a comparison that, the meaning of a word only becomes clear when you see the word in a sentence. However, to understand the meaning of the sentence the accumulation of the individual words is required.

The hermeneutic circle is related to Heidegger's concept of *Dasein*, and is tied to the acknowledgment that the self and the world are always united. *Dasein* does not translate well into English but has been understood as meaning being there. Dreyfus (2000:263) states that Heidegger uses "*Dasein* to describe our connectedness to the world".

Smith takes the original visualisation of the circle, which conveys the on-going process of engagement with research, one step further by suggesting that there is a separate second and smaller circle illustrating the interpretative and reflexive activity of the researcher. The interpretation and reflection occurs after each encounter with a new participant, and as part of this encounter, new knowledge provides further insight and understanding. Although Smith (2007) refers to this encounter being with a participant, these encounters could equally be with data, journal articles, or other researchers.

3.2.5 An Overview of Idiography in IPA

Another major influence on IPA is idiography. Smith et al (2009) and Smith and Osborn (2008) describe idiography with regards to IPA as being the researchers' commitment to each single case or participant's account that has been researched in its own right, before then moving on to the more general analysis of the data, alongside other cases or participant's accounts.

The process of taking an ideographic stance helps to situate participants within their own particular contexts, whilst exploring their personal perspectives. Therefore idiography starts with a detailed examination of each case before moving to general claims. As I gained more experience of research methods, particularly data analysis. I was unsure how this approach differed from that of a traditional thematic approach. IPA "is committed to the examination of how people make sense of their major life experiences" (Smith 2009:1). Exploring experiences "in its own terms IPA shares the view that humans are sense-making creatures and therefore the accounts, which participants provide, will reflect their attempts to make sense of their experience" (Smith 2009:3).

To explore how IPA used idiography within research I looked for examples of idiography from within IPA studies. Eatough and Smith's (2006) study looked at understanding feelings of anger from the perspective of an individual person. In particular the study focused on the role of feelings in an emotional experience, through qualitative analysis of the interview material provided by a single person. The idiographic approach manages to convey how the experience of anger is conveyed within the individual's life world. By utilising this approach to analysis, it gave a 'what it's like' component to the phenomena. The rich verbatim quotes within the analysis enabled a deeper understanding of the phenomenon for the reader.

Bramely and Eatough's (2005) study explored a participant's experience of living with Parkinson's disease. The study aimed to explore the lived experiences of an individual with a chronic degenerative disorder. The research explored the personal (idiographic) experiences of living with Parkinson's disease. The article demonstrated, by using verbatim quotes, how the superordinate themes were developed. During the discussion section the identified superordinate themes (which is a term used within IPA, amongst other approaches, to explore how themes emerged) were explored further using the scholarly literature to support the identified themes.

Robinson's (2002) exploratory study of one man's perspective, after his wife had a termination of pregnancy due to foetal abnormalities, explored how reflexivity is used within IPA. Within this idiographic account reflexivity was utilised by Robinson in order to fully rationalise her choice of specific analysis, which fits well with the characteristics of a high quality IPA study. As the reader it was appealing.

Robinson's rationale for the study was clear, which is reflected in the data analysis, alongside Robinson's personal reflexive account of similar experiences in her personal life.

I was particularly drawn to the concept of idiography and I think that this aspect of IPA convinced me to adopt this as my research methodology. As it took into consideration each participant's stories separately, before looking at similarities between stories.

3.2.6 What are the Methodological Considerations Associated with IPA?

Analysis

IPA originated within psychology and according to Hadfield et al (2009: 758) works on the premise that "people have relatively stable ways of perceiving their experiences, which are influenced by language, thoughts, feelings and physical experiences". Therefore, the researcher plays an active role in both data collection and analysis, as they are required to interpret the person's mental and emotional state, and how this differs from what he/she is saying. This requires the researcher to adopt a variety of different skills in order to begin thinking interpretatively. This process will enable rich experiential descriptions of experiences to be heavily grounded in the participant's own words, which can then be interpreted into an alternative account by the researcher (Smith et al., 2009).

IPA as an approach is “committed to how people make sense of their major life experiences” (Smith et al., 2009:1). A fundamental principle within IPA is the acknowledgement “that people are sense making creatures and therefore the accounts which participants provide will reflect their attempts to make sense of their experience” (Smith et al., 2009:3). IPA examines cognitions and emotions, which are underlying in descriptions of the participants’ experiences. The analytical process is therefore a fluid process which involves engaging with the participants with the analytical process involving flexible thinking, the process of reducing themes and revision of ideas/concepts (Smith 2009).

The analytical process that is being described, which is both interactive, cyclical and inductive in nature, is no different to other qualitative data analysis methods. With this in mind it might be more appropriate to consider IPA as a stance when interpreting data analysis rather than a distinctive method (Smith 2009). However, Larkin, Eatough and Osborn (2011) dispute this by stating that IPA goes beyond a traditional thematic analysis, as IPA analysis is the idea that human beings are ‘self interpreting beings’. Therefore within IPA there is a strong emphasis placed on individual idiographic accounts and IPA is committed to understanding the participant’s perspective through the researchers’ perspective. Despite Larkin, Eatough and Osborn’s (2011) claims, I still remained unclear how this approached differed from traditional thematic analysis.

After reading more about IPA, I began to explore how knowledge was generated within this approach and what that might mean for my own research study. I believed that IPA would offer me a systematic, phenomenological, focused approach, which enabled me to interpret participants’ accounts within the context of their personal meaning making. As a researcher this psychological focus appealed to me as it gave clear structure and a logical process to follow, whilst interpreting data that had been

generated as a result of carrying out in-depth interviews. This approach to qualitative research was also appealing as it acknowledged the uniqueness of individual sense-making involved in processing experiences, which then enabled people to make sense and add meaning to the experience from their own position and context of their personal/social worlds. This emphasises the theory that no two person's recollection of the same event will in fact be the same, but may share similar meanings. This concept is explained further within IPA as people make sense of the choices they make, and revise their understandings (and hence their thoughts). They can use this new knowledge and insight to change the way they think, feel and behave. This is referred to within IPA as double hermeneutics.

3.2.7 What Does 'Double Hermeneutics' Mean?

Smith (2009:3) defines double hermeneutics as being the process by which the "researcher is trying to make sense of the participant trying to make sense of what is happening to them. This captures the dual role of the researcher. He/she is employing the same mental and personal skills and capacities as the participant, with whom he/she shares a fundamental similarity – that of being a human being'. At the same time the researcher's sense-making is second order, he/she 'only has access to the participant's experiences through the participants account of it" (Smith, 2009:3).

IPA also emphasizes that research is a dynamic process with an active role for the researcher as part of this process. "The researcher is making sense of the participant, who is making sense of what is happening to them" (Smith 2009:3). "The researcher is making sense of the participant, who is making sense of x. This usefully illustrates the dual role of the researcher as both like and unlike the participant" (Smith 2009:35). "The researcher like the participant, is a human being drawing on everyday human resources in order to make sense of the world. On the

other hand, the researcher is not the participant, s/he only has access to the participant reports about it and is seeing this through the researcher's own, experientially-informed lens" (Smith 2009:36). This observation, with regards to the role of the researcher, recognises the difficulty of being able to bracket off thoughts, as the researcher's meaning systems are always present. Thus double hermeneutics is the acknowledgement that the researcher is part of the research process.

3.2.8 Criticisms of IPA

Within the literature there is a healthy debate between Giorgi (2010) and Smith (2010) which spans across several journal articles with regards to IPA as a research methodology. Giorgi raised concerns with regards to IPA's stance on developing a natural or phenomenological attitude and the use of the researcher's pre-understandings.

Giorgi was concerned that researchers who did not set aside their presuppositions and pre-understandings would affect the quality of the research they produced. However, within IPA it is suggested that pre-understandings and presuppositions will change and alter as a result of the research process. Finlay's views (2008) support this by suggesting that pre-understandings aid researchers' interpretations and therefore advocated their use of IPA as part of the research process.

One of the main critics of IPA is Giorgi (2010) whose criticisms stem from two sources: the lack of any real foundation of IPA in phenomenological philosophy and the lack of 'some sense of methodical discipline' (Giorgi 2010;5) in terms of how IPA is undertaken. Concerning his first criticism Giorgi suggests, as described by Smith and Osbourne (2003) 'phenomenology is defined as the study of the experiential world of an individual' and so 'it would have been a lot clearer if the originators of IPA had termed the method Interpretive Experiential Analysis' (Giorgi 2010;5-6). Giorgi's

second criticism is based on the lack of potential for replication of an IPA study and so in one sense Giorgi can be seen as attempting to apply positivistic criteria to a non-positivist approach to research. Conversely, Smith (2010) defends IPA based on this point. Giorgi also suggests that “any other competent researcher should, in principle, be able to ‘see’ or ‘discover’ whatever the principal researcher saw or discovered (Giorgi 2010 :9). Therefore the lack of transparency in the way that IPA studies are carried out is also being questioned.

Allen-Collinson (2009:288) points out “these are by no means specific to phenomenology but a general goal of much qualitative research in general, the rationale is fundamentally blunted and it is left to the reader to speculate as to why a phenomenological perspective in particular was chosen”. Thinking back to my own research I intend to utilise Heidegger in order to ensure that my research utilised a phenomenological perspective. I used the work of Heidegger as I felt that within IPA, the exemplar studies that I used, and also within Smith’s (2009) textbook, the phenomenological aspects of IPA were weak and not clearly justified. Allen-Collinson (2009) also raises concerns about the use of IPA with regards to: the phenomenological-interpretational balance in some IPA research; the over reliance on semi-structured interviews as the primary method of data collection; and the use of various forms of thematic content analysis, to examine the participants’ understandings of a phenomena. The more familiar I became with research analysis the more I agreed with Allen-Collinson’s (2009) comments, as I began to struggle to differentiate what made IPA analysis different to thematic analysis.

The use of IPA in social sciences continues to be open to debate. The issues explored above aim to raise awareness with regards to some of the problems that may occur when researchers are considering undertaking an IPA study.

3.3 The Role of Reflexivity

“Reflexivity allows the researcher to acknowledge their role in the creation of the analytical accounts” (Finlay, 2003:110). As such, I could therefore use my experiences of being a HIV nurse to help interpret my research data. As a result of this I began to understand the value and concept of reflexivity in relation to my own work. This led me to wonder how this would relate to my study and how I would capture this for the reader. I turned to the literature for guidance to see how other researchers had presented this aspect. Both Rowarth (2011) and Forde (2011) have helped to shape my understanding of how reflexivity can be articulated within my research study.

When researching experiences of living with fibromyalgia, Rowarth, (2011) clearly outlined her position statement as a therapist who is also living with fibromyalgia. There is a clear, reflexive section which explores the author’s experiences of living with fibromyalgia and how this would be used to add a deeper layer to the analysis section. The author’s position provides a transparent and reflexive acknowledgement of the frame of reference, which has underpinned her analytical process. Rowarth (2011) uses a reflexive journal in order to capture her thoughts throughout the research process, which enabled her to explore some of the issues that the participants had discussed in their interviews.

Similarly, in Forde’s (2011) work, reflexivity issues are clearly explored as she places herself within the research stating her rationale for undertaking her research with transpartners was based on her also being a transpartner. There is a statement

about her feelings and position within the participant's information sheet. Ethical issues are also clearly explored in relation to her research approach.

Prior to reading Rowarth, (2011) and Forde's, (2011) work I became concerned that being a HIV specialist nurse would impact on the chosen study. I was concerned how I would highlight this to the reader and produce a rigorous piece of work. I could now see how my perceived 'bias' would help not hinder my work. I could also see how my position would help me to produce an insightful and yet rigorous piece of work. Throughout the thesis I will use methods to engage with the reflexive process alongside patients' stories to explore and illuminate concepts.

3.4 Poetry

I wanted to present my findings in a way that would capture the 'essence' of participant's experiences (Ely 2007, Glense 1997), as well as engaging the reader in a dialogue and reflexive experience. I became interested in using poetry within my work after reading research that had utilised this approach as it introduced me to alternative ways to present my findings.

"Writing up interviews as a poem honours the speakers' pauses, repetitions, alliterations, narrative strategies, rhythms, and so on. Poetry may actually better represent the speaker than the practice of quoting snippets in prose" (Richardson 1994:522)

Richardson (1993) believed that the purpose of the research poem was to be both aesthetic and empathic with its greatest strength being that it conveys the emotional world of the researcher effectively. Whilst developing a poem, the researcher selects the participants' dialogue and represents this in a non-traditional way. The poem may

highlight different issues, help to clarify a particular account, make the account more compelling, or help the reader think about participants' lived experiences differently.

The use of poetry in research has been variously labelled as poetic transcription (Glense, 1997, Madison, 1991; Richardson, 2002), ethnographic or anthropological (Denzin, 1997), narrative of the self (Denzin, 1997), investigative poetry (Furman, 2003), auto-ethnographic poetry (Furman, 2003), simple poetry (Richardson 1997) or found poetry (Butler-Kisber 2002, Dewey, 1938, Sullivan, 2000).

For the purpose of my research I narrowed my reading down to work that focused on research poetry, transcription poetry or found poetry, as this appeared to be the most dominant form of research poetry (Glense, 1997, Richardson 1994, 2002).

Researchers create research poems from participants. Typically these poems come from the research interview transcripts. Found poems refer to poems authors create from existing texts, for example poetry, novels, and speeches. For the qualitative researcher, the text can be transcripts, artefacts, newspapers, social media sites and so forth. Richardson (1994) first brought found poetry to research as a way to represent qualitative literature reviews stating 'I decided to use found poetry, which takes the words of others and transforms them into poetic form to re-create lived experience and evoke emotional responses ' (Richardson 1994:205).

Glesne (1997: 205) inspired my exploration of what she called 'poetic transcription. Her work with this experimental form of writing arose out of an interest in Richardson's work (1992, 1994) which focused on transforming interview transcripts into poetry. Although Richardson did not describe the process of how to do this, Glesne identified three rules that she used to guide the process of poetic transcription. These were as follows:

1. The words in the poetic transcription would be that of the participant, not the researcher.
2. She could extract the phrases from anywhere in the transcription and juxtapose them together.
3. And finally, she would have to keep enough of the participant's words together to present the poem according to her or his 'speaking rhythm'.

I have chosen to use these rules when crafting my own text into poems. Within my data analysis I extracted phrases verbatim from participants' narratives, in particular the first part of the data, which explored why the participant came in to HIV nursing and juxtaposed these phrases together to create a poem. The poems were then used to introduce the reader to the participants.

I had hoped to use poetry within the main findings but this was not as successful as I first hoped. In the process of using research poetry I had initially started representing the reasons why participants had come into HIV nursing. This was the opening question that I had asked participants to ease them into the research. Poetic representation seemed to work well within this section. I was able to present the reasons why the participants had come into HIV nursing in poetic form without losing any of the meaning that the narrative contained. When I tried to use the same principles within the main data, reducing the narratives to poetic form did not capture the full nuances that presenting the whole narrative did. After careful consideration, reflection and discussions within supervision, I decided to return to representing the rest of my data using a more traditional narrative approach. Therefore, I have decided to only introduce my research participants in poetic form in an attempt to

make my research more accessible for some readers and assist in the dissemination of my findings. I am keen to ensure that my research findings are disseminated to honour the time that participants have given to the project. I agree with the work of Wolcott (2009) who believes that research cannot be said to have been 'done' if it is not disseminated.

Due to the subjective nature of the phenomena being investigated, I felt that using poetry would allow me to explore and attribute meaning to a variety of different experiences that had led participants to work in HIV nursing. By presenting my research participants in this way I wanted to break from a traditional descriptive representation of who they were and why they had come into HIV nursing. I felt that presenting my participants in this way would enable the reader to position them with regards to their subsequent story and how they might view HIV care. Whereas I was keen to explore the use of poetry within my research, I began to realise that at this stage of my research career I did not have the skills I needed in order to undertake this. Whereas the first part of my data analysis lent itself well to this type of data representation (when participants gave their reasons for choosing HIV nursing) further narratives did not lend themselves well to this approach and I therefore returned to a more traditional way of representing data within the analysis section.

3.5 Final Reflections on Using IPA

In summary, to understand the IPA genre, I consulted the scholarly literature and numerous IPA studies. Whilst reading a number of studies it was hard to extrapolate what made them IPA, as opposed to generic qualitative research. In order to facilitate and develop a deeper understanding, a number of high quality IPA studies were consulted. In order to assist with this I used Smith's (2010) guidance on what makes a good IPA study.

IPA research focuses on a phenomenological understanding of the participant's worldview and seeks to understand the meaning-making that occurs when participants share their experiences. The approach identifies the role the researcher plays in the research process and generation of data. IPA offers a stance in order to analyse data, which is interpretative and gives emphasis to the participants' wider social and cultural world, which is then linked to theoretical knowledge to support the representation of participants' experiences.

The chapter so far has outlined my own interpretation of what IPA means to me and I have suggested some key elements that I feel constitute a high quality IPA study. I have used these interpretations to guide my interpretative way of thinking throughout my research journey.

3.6 Methods

I will now go on to discuss how I administered my research study, what methods I used, how I generated the data, including participant recruitment and how the data was then analysed.

3.6.1 Participants and Recruitment

In order to recruit participants to the study I used a purposive sampling strategy consistent with IPA. I aimed to recruit a homogenous group for whom the research question was meaningful and who could give their idiographic perspective on that experience (Smith et al., 2009). I was granted permission from the chair of the North West HIV nurses network to email the membership, details of my study (N=150). Within IPA, when considering the recruitment of participants, one of the main criteria is that they should be experts within the area under investigation and be able to grant insight into that area (Reid, Flowers and Larkin, 2005). IPA studies work well when the participant has an interest in the phenomenon under investigation. Therefore,

participants within the study were deemed experts by virtue of them working at a senior level for 12 or more months caring for people living with HIV. I recruited 10 participants who expressed an interest in taking part in the study and were willing to share their experiences with me. In line with IPA sample sizes I had pre-set a recruitment limit of 10 participants. Despite having a pre-set limit only 10 nurses responded to my invitation to be a part of the study. I therefore, I did not have to exclude any nurses from my study.

I used semi-structured interviews as the means of data collection, which is in line with IPA traditions. During the recruitment process all participants were given an information sheet (Appendix 1) explaining the intentions and conditions of the interview two weeks prior to attending a pre-arranged interview. An opportunity was provided for participants to ask any questions at the start of the interviews. None of the participants felt that they required any further information prior to signing the consent form.

In order to gather background information on participants, such as the length of time they had been working as a HIV nurse, and to ensure that the participants met the study's inclusion criteria, demographic details were collected during the interview process and helped to provide information for the participant's pen portraits (these are included within the data analysis section).

At the interview the aims, nature and confidentiality of the study were discussed. It was noted, by me that anything discussed in the interview would remain confidential unless participants disclosed anything indicative of risk (either to themselves or others), in which case I would have to disclose this information to the appropriate person, who would be identified based on the nature of the concerns raised, e.g. participant's line manager. Also, as an NMC registrant, any information given in

relation to unsafe practice would need to be discussed. If such an occasion arose, I would discuss it with the participant first, prior to passing on my concerns. I was keen not to make any promises I could not keep. I made participants aware of the clause of confidentiality at the start of the interview in order for them to make an informed decision as to whether to take part or not.

I was concerned that participants may disclose things that they may later wish they had not, therefore participants were sent a copy of their transcript to ensure that they felt it was reflective of what they had said and had wanted to say within the interview. This also provided them with the opportunity to withdraw the transcript prior to analysis, in part or in full. All participants responded and all were happy with the content of the transcript. This process is considered good practice within IPA studies and is advocated by Lincoln and Guba (1985) as a way of adding validity to the research process. However, the process of respondent validation (member checking) was more in line with what I thought was my ethical responsibility to the participants. I felt a sense of responsibility to give the participants an opportunity to withdraw what they had said before I engaged in the analysis process.

3.6.2 Data collection

3.6.2.1 The Interview Process

Within IPA interviews are considered the most appropriate way of collecting data, with one-to-one interviews being the most common form of data collection (Flowers 2008, Smith 2011). Based on interviews being the accepted means of data collection within IPA, I chose to use semi-structured interviews within this study.

Semi-structured interviews were chosen instead of unstructured interviews as a result of my lack of confidence in my ability to conduct the interviews without a

prompt or without carefully considering what I would like to ask prior to engaging in the interviews. I therefore decided to use an interview schedule to help structure the interviews.

To ensure that the data collected is of rich quality the researcher needs to find a way to enable the participants to consider and reflect on their experience. Therefore it is useful if the researcher can create an environment that enables the participants to 'dwell' in their experiences that are being enquired about (Eatough and Smith, 2006 a).

With this in mind, participants were interviewed in a location that was private and away from their clinical area. All participants were given a choice of where and when they would like to be interviewed. All participants chose their own work location and did not object to the interview being recorded.

In order to try and put participants at ease and to create an environment where they felt able to engage with the interview, an opportunity was provided for any questions or concerns to be aired within the interview. I thanked the participants for taking part and verbalized my interest in their experiences. Throughout the interview minimal verbal prompts were used. I also employed the use of encouraging body language and showed an empathetic curiosity to hear their experiences.

It has been acknowledged that research interviews may provide therapeutic experiences for participants (Colborne and Squae 2005). However, this might not be the case for the researcher as they may be undertaking research that touches on sensitive subject areas and, post interview, could be left feeling emotionally drained (Gair 2002). Often researchers, particularly lone researchers, are left to deal with the emotional fall-out from the interviews and are unable to find someone to talk to about

their experiences (Brannen 1988). With this in mind, it was important that I sought regular clinical and academic supervision, whilst acknowledging the impact the nurses stories' from practice were having on me.

3.6.2.2 The Interview Schedule

Smith, Flowers and Larkin (2009) amongst others, suggest that the interview is often seen as a conversation with a purpose, with the skill being the interviewer's ability to enable the participant to recall their experiences, and to engage in 'real time reflection' of their experience (Eatough and Smith, 2006 b).

I liked this as a concept and invested a lot of time thinking about how I would do this within my own study. What questions would help to provoke this state? What questions could I use to gain access to my participant's worlds?

Smith and Osborn (2008) encourage the researcher to think proactively about the broad range of issues that may be explored by the participant within the context of the interview whilst bearing the research question in mind. As a result, I decided to develop a semi structured interview schedule which was designed to guide, and not dictate, the interview (Appendix 2 shows a copy of the interview schedule).

The development of the schedule involved anticipating questions that may open up both personal and relational experiences when nurses elicit the patients' concerns. I wanted to develop questions that would enable me to see what personal factors, such as previous life experiences, the nurse brought to the interaction and how relationships with patients were developed.

I piloted my interview schedule with three nurses, who did not currently work in HIV care and therefore did not meet the inclusion criteria for the study. However, these

nurses previously worked within HIV care and were therefore able to answer my questions. As a result of the pilot interviews, I revised my interview schedule. After much thought it was considered an initial question was required in order to ease the participant into the experience of recalling relevant situations or contexts, which led to me asking participants: 'What led them to work as a HIV nurse?'. With this question I hoped that I would begin to hear some of their motivations for becoming a HIV nurse, whilst easing them gently into a reflective way of thinking.

The second question I asked was 'Can you tell me about a patient situation that you will never forget?'. The question eased participants into recalling a situation, leading them closer to the theme of eliciting patients' concerns by asking them to recall meaningful experiences relevant to the research topic. This allowed them to somehow re-enter the experience with active listening, empathy, probing questions and non verbal cues. The rest of the questions were designed to further open the experience in a way that was relevant to the research question. The questions enabled a focus on personal reactions to patients' concerns, eliciting patients' concerns, ways of making sense of these concerns, and skills used once these concerns had been highlighted.

A closing question was designed to encourage participants to address anything relevant to them that previous questions had not captured. This question helped participants share any thoughts or reflections that had come to mind as a result of engaging in the interview. It also helped to facilitate a natural closure for the interview.

3.6.2.3 Transcribing

All the interviews were transcribed verbatim. There is a wealth of information available in relation to the benefits of the researcher transcribing the tapes

personally. I was a little unsure as to whether the extra effort involved in this process would be worth it. It was suggested that by personally transcribing the audiotapes I would gain an extra level of analysis, picking up on any nuances, hesitations, pauses, emphasis on words or the many other ways that people add meaning to what they say (Jenk, 2011:75).

I meticulously transcribed three of the interviews and felt that, although there were certain benefits from transcribing the interviews, the time involved in transcribing was hindering my ability to move forward with my research. I therefore decided to have the rest of the interviews transcribed professionally. In order to remain as close as possible to the data, I listened to and read the transcripts until I could hear our voices and felt myself back in the interview whilst reading the text. I felt that this allowed me to reach the same level of analysis that transcribing them personally would give me. (Appendix 3: An example of a participant transcript)

3.6.2.4 Ethical Considerations

Prior to commencing data collection for the research project, ethical approval was successfully gained from the following departments; Manchester Metropolitan University research and ethics committee, and North Manchester General Hospital's research and development department (Appendix 4: Example copies of Ethical Approval).

I conducted the interviews referring to the interview schedule regularly, whilst at the same time allowing the participant to tell their story. Despite my initial concerns that participants would become distressed as they recalled difficult experiences, none did. Each participant was invited to contact me at any point after the interview in case they began to feel distressed or uncomfortable about issues, that arose from the

interview. Participants' confidentiality was paramount and pseudonyms were used within the data collection and transcribing.

Relationships and power became an important ethical consideration for me. I was aware that I was quite a well-known HIV specialist, both regionally and nationally. I did not want this to affect participants' ability to be open with me or share their experiences out of fear that this would make it uncomfortable for them to access courses or future research studies. I reassured participants as much as possible, by providing them with information and being open and honest. Gray (1994) describes another issue that may be present within the interview relationship-ego threat. This related to the respondent perceiving that a particular response may reflect badly on him or her. Gray argues that this cannot totally be eliminated, but only reduced by the interviewer taking a non-judgmental attitude and upholding promised anonymity. Due to the focus of the research study, I was mindful that participants might feel that I was challenging their practice. I therefore tried to appear encouraging, friendly and neutral throughout the interview. Within the data analysis the challenges this posed to me as a researcher was explored using my reflexive journal.

3.6.2.5 Reflexive Journal

I have kept a reflexive journal throughout my professional doctorate journey, in order to enable the recording of various factors that have impacted on the development of the research and how my research has impacted on my development. Finlay (2003:20) suggests "keeping a journal as part of reflexive research can help to focus internal responses to being a researcher and to capture changing and developing understanding of method and content".

The reflexive journal assisted in enabling me to reflect on the multiple roles I had within the research. This included the impact that the research had upon me

personally/professionally, and the potential effect that the research could have on my relationships with participants. Within the reflexive journal I was able to record the impact my perceptions might be having on the research, alongside the negative and positive feelings that I was experiencing during the research process (Finlay, 2003).

The ability to record my personal thoughts within the reflexive journal allowed me to process thoughts and/or feelings objectively, enabling me to view my participants more openly, in particular participants that I was struggling with due to my unacknowledged thoughts and feelings. I was mindful that I did not want this to prevent me hearing the participant clearly or influence my ability to make sense of what I was hearing.

For me, the reflexive journal proved invaluable in shaping my research and guiding my journey. I was able to 'get out of my head' and to put onto paper lots of thoughts and feelings which ultimately led to a deeper understanding of the participants' narratives.

There is a danger that a reflexive approach can appear pretentious, with the researcher being accused of navel gazing, therefore potentially alienating the reader, instead of offering further understandings of the research process. I hope to avoid a narcissistic stance by ensuring that the reflexive extracts, used within my research are used to help aid understanding of my research. I began to view the reflexive approach as one similar to an ethical approach and believe that this should be undertaken throughout the study and integrated throughout the research process (Dahlberg 2008). By adopting this approach the study becomes more transparent to the reader, enabling an increased sense of trustworthiness in the research process and findings. I have used my reflexive journal to help guide and shape my pre-understandings and explore my motivating factors for undertaking the study.

3.6.2.6 Pre-Understandings

Pre-understandings (based on Geanollos, 1998)

In order to establish what my pre understandings were, I began to ask myself the following;

- What do I perceive the nature of HIV nursing to be?
- What are my strongly held beliefs about patient-centred care?
- What are my stories from my practice as a HIV specialist nurse?
- What are the key statements from these stories that make up my pre-understandings?

As a HIV specialist nurse I hold my own pre-understandings about the phenomena. It wasn't until the pilot studies that the influence of these pre-understandings came into consciousness. Undertaking the pilot interviews, I became pre-occupied with stories from my own practice. At times, these stories held me at a distance from my participants. I was locked into my own thoughts/stories and therefore did not allow the participants' stories to be heard. As the participants were talking, my own thoughts and stories would come to mind. These thoughts were stifling as if I was catching my breath and in doing so prevented the participants' stories from coming to life. I therefore decided to explore these stories from my own practice to enable me to extract statements that would act as my pre-understandings.

The stories from my practice will be used alongside participants' stories to illuminate concepts within the analysis and to remind me of the influence they have on the research and on me.

Reflecting on these thoughts, feelings and stories have been essential as they could have led me to premature interpretative closure, resulting in me leaving the

hermeneutic circle too soon, preventing a deeper layer of analysis being revealed. If I had not engaged in this process of addressing fore structures/pre-understandings it would have placed me at risk of confirming my own assumptions and beliefs rather than revealing the truth about the phenomenon under investigation (Geanollos, 1998).

Engaging in this process has helped me create the following statements:

Statement One: Non-judgmental practice is fundamental to HIV care.

Statement Two: As a nurse I aim to provide a place of sanctuary for HIV patients where they do not feel judged.

Statement Three: Emotional needs are often overlooked in favour of physical care needs.

Statement Four: Emotional and psychological care is an essential component of patient care.

Statement Five: HIV nurses use a lot of intuitive practice to provide care.

Statement Six: The good nurse is emotionally self-aware.

Statement Seven: Patient-centred care is central to good nursing practice.

Statement Eight: Providing patient-centred care is challenging for the nurse as outcomes are harder to monitor than other areas of care.

Statement Nine: Patient-centred care comes at an emotional cost to the nurse

Statement Ten: Patient-centred care facilitates empowerment.

From the statements generated I have made the following assumptions:

- Patients value patient-centred care
- Patient-centred care is difficult for nurses as it is hard to measure and is often overlooked in favour of physical care needs.
- HIV patients have a lot of invisible needs that nurses within this field require a variety of skills to assess in order to provide appropriate care for them.

Smith et al. (2009) state that when engaging with the text that our pre-understandings become apparent. Reading the text helps to remind us of what we thought about it beforehand. This was definitely my experience, as my thoughts, feelings and assumptions were triggered as a result of engaging with the data. I was also surprised at how stories and memories dating back 18 years began to emerge to help offer an understanding.

3.6.2.7 Analysis Quality and Validity

A limitation of IPA is with regards to the findings being specific to a particular group of participants, and the co-constructed analysis of the data generated, being heavily linked to the researcher. If different participants had been recruited then perhaps different results would have been generated. Similarly, a different researcher with a different academic background, different clinical experience or a different epistemological position, would have produced a different analysis. Therefore, IPA does not claim generalizability but offers insight into a particular phenomenon (Smith, 2010).

IPA's accessibility, flexibility and methods can be mistaken for lack of rigour and the subtlety, and complexity of phenomenological aims and origins can be overlooked.

Rigour refers to the overall thoroughness of the research which includes the appropriateness of the sample, the quality of the interviews and the overall completeness of the analysis undertaken (Smith, 2010).

It is important for qualitative research to be evaluated in terms of quality, although by different criteria than those applied by quantitative research (Smith et al 2009). There is a debate within the academic community over the criteria for evaluating the validity of qualitative research. This has, according to Smith (2010), been prompted by

qualitative researchers' frustrations at their work being evaluated according to quantitative criteria (such as replication and rigour). There has, therefore, been a move towards assessing the quality of qualitative research differently. There have been a variety of different ways proposed of ensuring quality within research projects. Smith (2010) suggests how qualitative research could be judged and offers commitment, transparency and plausibility as options. Guba and Lincoln (1989) promote credibility, dependability, transferability and confirmability as four major criteria on which qualitative research should stand. Meleis (1996) identified eight criteria: contextuality, relevance, awareness of identity and power differences, empowerment, a flexible approach, communication skills and reciprocation.

These principles were reflected on and adhered to throughout all stages of the research process. To help with this process I kept a reflexive journal which I utilised throughout the varying stages of my research journey. I used the journal to record reflections about the interviews and any interpretations that occurred during the analysis process. Discussion that occurred during supervision helped to monitor the themes that were developing, ensuring that their relationship to the original data was clear. This then acted as a credibility check. As themes were developed a table containing information that could be traced back to the data was brought to supervision. This was done to ensure that the themes and conclusions were firmly rooted within the data.

Within my research I have tried to demonstrate a clear decision making trail; and ensured that there was appropriate use of reflexivity and transparency with regards to how my data was analysed and how the themes had emerged.

After establishing how I was going to undertake my research, I then turned my thoughts to how I would begin analysing the data that had been generating.

Chapter 4: Introduction to the Analysis

Collecting data through interviews felt relatively easy during the data collection phase as it appeared familiar compared with other methods of data collection. The problem arose at the stage of analysis. How would I make sense of what seemed to be so much useful data and then represent it to the readers?

Coffey and Atkinson (1996) noted how overwhelming naturally occurring data could be. Once safely recorded and obtained, there are the problems associated with analysis of the material. After all, it has not been neatly served up, into pre packaged categories, and structured responses. It remained in its rawest form. .

Pollick (1991) suggested that there is a need for researchers to be transparent in the way in which they have managed a large amount of data and then how they have made choices about reducing the data. These complex decisions need to be supported and discussed as part of the analysis process. Pollick (1991) believed that this is a challenging, time consuming, and complex issue within qualitative research.

Due to my over-enthusiasm, mixed with a fear of 'getting it wrong', I analysed three transcripts systematically and very precisely following a series of steps, strongly influenced by a dissertation that I found useful at the time as itself followed five-step procedure detailed by Smith and Osborn (2008) (Blank 2011:119).

Although they state that this is not a prescriptive methodology, it can be adapted by the researcher to meet their own personal way of working. In my desire to get the analysis 'right', I somehow managed to overlook this and having found a description of how to proceed with the analysis (Blank 2011) in a case-by-case, idiographic manner followed this procedure as detailed below.

Stage One – A close reading of the interview transcript took place. I augmented this process by listening again to the interview recording as I read the transcript through. I used the left hand of the margin of the transcript to note what seemed interesting or significant about what the participant was saying. I was looking for contradictions, echoes and amplifications, similarities and differences, use of language, and pieces of the text that gave a sense of the person.

Stage Two – Once I had gone through the transcript as described above, I would return to the beginning of the transcript and use the right hand margin to document emerging theme titles. Smith and Osborn (2008) remind researchers that at this stage all text is treated as data and no attempts should be made to omit or select certain passages, while at the same time, the researcher does not need to generate themes from every selected text.

Stage Three- At this stage I clustered themes together as Smith and Osborn (2008) suggested at this stage it may be useful to complete a directory or passage of text to illustrate the identified themes. I represented this within my analysis in tabular format.

Stage Four – At this stage I devised a ‘master’ table of themes for each participant, again as recommended.

Stage Five – Following completion of the analysis of all 3 interviews as described in stage 1-4, I then devised a ‘master’ table of themes for the whole group of 3 interviews.

Procedure for analysis (adapted from Blank 2011 p119-122)

As a result of following the steps outlined within the IPA method as detailed above, I became overwhelmed, confused and somewhat fatigued by the amount of energy involved in this method. I remember sitting on the floor surrounded by cut up pieces of transcripts, trying to organize them with a certain amount of creativity and flair. I remember feeling like Jonny Depp in the movie, *Edward Scissorhands*, frantically cutting, with pieces flying everywhere in order to create a masterpiece.

As I sat there surrounded by clippings of stories, I wondered if this is how an editor felt whilst trying to piece together a movie, surrounded by cut up pieces of film reel containing imperfect scenes or scenes that the director no longer felt fitted with the bigger picture. The pieces that were on the floor also told a story; one I felt should be told, but how?

Once I had colorfully arranged my cut up pieces of narrative on different pieces of card, each representing different themes, I sat there patiently hoping for two things. Firstly, that the cat didn't come in and jump all over them. Secondly, I hoped that what Smith (2004) suggested would happen; that as part of this process I would see a magnetic attraction between certain themes pulling them together, in order to try and help make sense of the data as a whole.

Sadly, this did not happen and I was struggling to thematise experiences by cutting a narrative story into chunks as I felt this approach weakened what the participant was saying and was beginning to feel forced. I also did not want to manufacture accounts by making narratives neatly fit or cut out parts of the story.

Confused and looking for guidance I turned to the plethora of IPA research studies that I had collected which were now sitting on my desk. I read numerous studies' on

analytical processes before coming across Collins and Nicholas (2002:5). They argue that to undertake in-depth 'interpretative engagement with the respondents text', diluted the data through disaggregation and unitization. They questioned "whether IPA in its search for connections, similarities or divergences across cases misses a richer seam of data" (Collins and Nicolson 2002:5). They go on to argue that they were unsure as to how an IPA approach differed from that of general thematic analysis.

After reading Collins and Nicholsons' (2002) challenges against IPA analysis, I began to acknowledge my own struggles with my chosen method. I remember hearing a voice of reason coming through the pages of the textbook that I had turned to for guidance. IPA "is not a prescriptive approach. Rather IPA provides a set of flexible guidelines, which can be adopted by individual researchers in light of their research aims" (Smith and Osborne, 2008:45). Initially the novice researcher may follow the steps quite closely until they begin to develop an IPA way of thinking. This gave me new hope and a sense of relief with my chosen method.

When reflecting on how to interpret the data for this study, I wanted to let the voices of the informants be heard in as much detail as possible within my research. I remained convinced that IPA's idiographic stance could assist me with this.

The remaining seven interviews were analysed following IPA guidelines (Smith,1996). By the time I had reached this point in my journey, I felt I had begun to develop an IPA way of thinking. The style of analysis that I was beginning to lean towards was a more hermeneutic phenomenological approach that seemed to fit with my methodological concerns, and appeared very suitable for the phenomenon. The hermeneutic circle appeared to be seducing me, tempting me to learn more about it in order to incorporate it into my work. Although at this stage of my research journey I

wasn't sure I understood the hermeneutic circle well enough to make any profound intellectual claims, I knew that this could be used to help me make sense of my participant's life in a meaningful way.

Returning to my data, the analytical process was followed fairly closely to that outlined in Smith et al.(2009), taking a more fluid format than previously alluded to. Each individual case was taken sequentially. Each transcript was read several times before initial notes were made. Smith et al.(2009) suggest that these notes should include descriptive, linguistic and conceptual comments. Descriptive notes focus on the substance of what is being said, staying close to the face value meaning. Linguistic comments note things such as pronoun use, metaphor, tense, tone and idiom. Conceptual notes, which are more explicitly interpretative, involve "a shift in your focus, towards the participant's overarching understanding of the matters that they are discussing" (Smith et al. 2009:92). These are informed by the researcher's own cultural horizons. For the next stage of the process I reduced and organised my initial notes into 'emergent themes'. The aim of this was to maintain the complexity of the data whilst being 'concise and pithy' (Smith et al 2009:92). Throughout this stage my own interpretative voice was encouraged to come into the foreground.

I listened to the recordings as well as reading the transcripts. I listened until I could read the transcripts and hear our voices. By doing this I felt myself back in the interview with my initial notes and reflexive journal helping me to reconnect with the interview throughout the analysis.

The more experience I gained using this approach, the more liberated, confident, interpretative and passionate I became about the process. Smith et al. (2009:88) noted the importance of 'spending time with' the phenomenon. I felt that I had become immersed within the data.

By using the hermeneutic circle (as previously discussed in the methodology section), I was able to use my pre-understandings and previous experiences to enrich the data, as opposed to invalidate it. The data was developed to create new meaning by using my pre-understandings, my background as a HIV specialist nurse, my personal reflections, the raw data and relevant literature available on this subject.

As a result of this process, I began developing emergent themes. Once I had established these emergent themes I went back to the data from the transcripts to look for further mention of these themes.

After undertaking a case-by-case analysis, the themes were then cross compared with the other transcripts and a decision was made to present the data more ideographically, using the exploratory themes common across all transcripts, in order to provide a deeper narrative.

In order to strengthen the analysis specific phenomenological influences were used to explore how nurses used their ways of being in order to provide care for patients and subsequently elicit patients' concerns, in order to provide patient centred care.

The phenomenological influences that have supported the analysis and established how the nurses within the study elicited patients' concerns have been previously mentioned in chapter 2, but will be briefly re-visited now. These phenomenological influences were Dasein, temporality, historicity, authenticity and presencing.

Dasein, was used to frame my understanding of Heidegger's philosophy to understand the different ways of being that influenced the nurses' ability to create a therapeutic relationship, that facilitated the disclosure of concerns. Temporality and historicity were used in order to frame the context in which HIV care was delivered that influenced the nurses' way of being. The nurses own historicity was also used

within the analysis to explore how their experiences shaped the care ? Authenticity and inauthenticity were used to analyse how the nurses used differing ways of being in order to elicit patients concerns. Finally, presencing was used in order to analyse the patient relationships that were described by the nurses and how the nurses' way of being within the relationships facilitated person centred care to develop, and so potentially leads to the patient being able to disclose their concerns.

Research poetry was also used when exploring participants' reasons for coming into HIV nursing, alongside personal reflections to allow for another layer of analysis. This is in keeping with Dean, Smith and Payne's (2006) view of IPA analysis being a layered approach, likening the analysis to peeling away layers of an onion.

Three themes are presented within the analysis these themes were deemed the most relevant and important, arising most frequently from the participants. These themes have been identified as, A way of being: HIV nurse's experiences; the nurse-patient relationship; and factors that impact on authentic care.

Before I present my findings, I would like to introduce my research participants and share with you another reflection of my experiences of caring for Joe.

4.1 My Research Participants Pen Portraits

Providing some biographical information about the participants makes them 'come alive' for the reader. The aim is to provide the reader with some holistic sense of the person, which contextualizes the analytical material (Silverman, 2013). Whilst I believe that it is important for the reader to have a sense of who the participants are, I have used caution when sharing the biographical information to ensure that the participants could not be identified.

With this in mind I would like to introduce you to the participants who took part in the study. I have selected the participants' reasons for coming into HIV nursing as a way of introducing them to the reader. The reasons why the participants came into HIV nursing was the opening question of the interview. It was only later whilst analyzing the data I realized how important this question was in orientating the participants' frame of reference when providing patient care. I have shared the participants' reasons with you, using their own words from their transcripts in poetic form. I have chosen to use a poetic format to introduce participants (as previously discussed in the methodology chapter) to try and capture for the reader the 'essence' of the participants' experiences (Ely 2007, Glense, 1997). It is hoped that by sharing the participants' reasons for coming into HIV nursing, it will help the reader when interpreting the data within the analysis section.

4.1.1 Harry

Harry is in his early 30s and has been working within HIV care for 5 years. Harry is very passionate about this area of care and in his spare time he is a devoted volunteer and advocate for a local HIV non-government organization who provide support for people living with HIV.

Harry is a very warm and genuine character with a relaxed persona, which made him easy to talk to. Harry is a natural narrator and uses his hands to communicate, making his conversations appear alive and flamboyant.

Misunderstood area
I was at university,
before I did my nurse training
I went to South Africa
working at school
HIV awareness
when I came back
I wanted to carry on
I worked with a charity
that worked with people with HIV

*I've also wanted to work with HIV
I kind of made it an effort
to get a job here
carried on doing my volunteer work,
initially worked on a ward
I wanted to work with people with HIV
for me
it was a misunderstood area
I felt I wanted to learn more myself
by kind of working in it*

4.1.2 Orla

Orla is in her early forties and has a warm, maternal persona. Orla has a very loud and infectious laugh, which reflects her warm and bubbly personality.

Orla has been working within HIV care for over 15 years and had much experience working with very complex patients.

During the interview, Orla appeared nervous at times and conscious of how she was coming across, although this became less noticeable as she began to passionately recall tales from her practice. She used these reflections very skillfully to help illustrate the points she was raising.

Caring side
*I've always had a caring side,
Even back in junior school.
I came out of school,
I was about seven,
With no vest on.
My friend had holes in hers,
So I gave her mine.
I've always had a caring side.
I've always been able to talk to people.*

4.1.3 Erin

Erin is in her late forties and looks younger than her years. She has a youthful fresh outlook on life and mischievous personality, which came through during the interview.

Erin came into nursing after a series of other career choices and decided early in her nurse training that she wanted to work in sexual health. Erin has a couple of years experience working with people living with HIV and appears motivated to continue her nursing career in this area of care.

Erin was very helpful during the recruitment phase of my interviews and encouraged her colleagues to take part in my research. Throughout the interviews Erin provided tea, biscuits, moral support and encouraging smiles.

Prior to Erin's interview, I had only met her a couple of times at local training events. As such, her help in recruiting participants to my study was both surprising and very well received.

Me, as a nurse
*It was an area
that I was always interested in
I did the volunteer program
I chose GUM
purely to work with HIV cohort
I found the whole condition very interesting
there are so many psychological elements to it
much more than I thought
Because of the stigma
never mind how much the HIV impacts on someone
I thought me, as a nurse
I'd like to work that route*

4.1.4 Shauna

Shauna came into the room and I instantly felt at ease. She came across as being very focused on providing psychological care and this was reflected within her

thoughtful answers to the interview questions. She displayed a certain amount of expertise and confidence with the subject area. It became clear from our discussion that Shauna was well educated and extremely well spoken.

Shauna shared a variety of different experiences of working with people living with HIV and appeared passionate about working in third world countries. The interview moved smoothly and was both informative and inspiring.

The fascinating appeal

*I've always been interested in HIV
since I was doing my training
always been interested
in working overseas
developing countries
that's what got me interested
in infectious diseases
if I specialise in HIV
I could work in a field
I've always sort of wanted to work in this field
I find the disease quite fascinating
I like the cohort patients
in the future
I would like to work overseas
with the experience
that I've learned here.*

4.1.5 Niamh

Niamh was a very passionate, knowledgeable participant. She had many years experience of working within HIV care, and could recall stories from her practice with ease. There was a sense that we were collaborating, a sense of solidarity, and I felt very privileged to be allowed into her world.

Niamh was very genuine and authentic throughout the interview. She seemed very interested in my research and wanted to learn more. Niamh was very respectful towards me and praised my commitment to HIV care. It felt very easy and natural to speak with Niamh, whose caring, warm nature appeared to fill the room.

I could go along with that
I started work in 1999
in sexual health
I just really enjoyed the HIV side
there were a lot of other needs
that the patients had
which I enjoy
the counselling skills, I developed
the multidisciplinary team working
I just thought this would be a good role
because I feel
I could you know
go along with that.
I felt it could be something that
I would be good at.

4.1.6 Louis

Louis was a very experienced nurse with over 25 years of practice working with people living with HIV. His experiences dated back to the first days of HIV when very little was known about the disease or how to treat it. I was hoping to gain insight into his diverse experiences of practice. During the interview I sensed that certain experiences remained too painful for him to talk about.

Louis had a natural authority, a father-like figure way about him. I went into the interview both excited and nervous about what would unfold.

Nursing challenges
Patients coming into Infectious diseases,
Patients with malaria or other such illnesses,
Presented challenges,
Nursing challenges,
Nursing knowledge, challenges,
Those patients came,
Were treated, known recognized treatments.
Their care pathway was easily planned.
The positive patients ,
The treatments were not defined,
They were still experimental,
People did not have
An automatic expectation of good treatment
Or good care.
More of a challenge as
Patients would return on a regular basis.

4.1.7 Zayn

Zayn was very warm and relaxed, joking from the kitchen as he put the kettle on to make me a cup of tea. He seemed genuinely interested in my research and what was involved in carrying out the project.

He had a loud voice and appeared very laid back in his chair as he spoke to me. He used humour to try and defuse challenging situations and often appeared jokey towards me throughout the interview.

He had lots of experience working with HIV patients and spent a lot of time within his role improving care and services for patients. Zayn appeared well motivated, ambitious and very committed to this area of care.

Lecture me on HIV
initially started off in A&E,
my interest in sexual health
and HIV
came from a lecture
I had quite a lot of lectures
on HIV
he was a HIV nurse
in the past
I didn't want to do HIV,
it was A&E
I wanted to do
from his lectures
it was down to him
I do think part of it
might have been
from personal experiences
it was like
the most horrific experience
ever
I sort of wanted to work in that area

4.1.8 Holly

Holly appeared very laid back and at times she seemed to be happy to be interviewed. Throughout the interview she came across as a very jokey, jolly,

confident character. Although, Holly had a wealth of experience working with a large cohort of people living with HIV, she seemed reluctant to let me into her world and share her experiences. At times during the interview it felt awkward and forced.

Not about the infection
*In sexual health,
It's not about the infection,
It's about the person,
You could see somebody with something,
That anybody else might think is innocuous,
Like warts or herpes,
For them it could be the end of the world.
Then you could see someone with HIV
And they would be completely fine about it.
It's not really the infection,
It's the individual
How they are reacting to it,
That you respond to.*

4.1.9 Alannah

Alannah arrived seeming relaxed and I quickly got the sense that she was comfortable. She looked straight at me and was happy to maintain eye contact, as we got involved in the interview, it felt that things flowed very naturally and effortlessly. At times Alannah spoke metaphorically to allow the stories she was telling to be explored further.

Alannah had just over 18 months experience of working with people living with HIV. Despite this relative lack of experience she had plenty of enthusiasm and experience working in other areas, including sexual health. She spoke freely of her initial reservation about coming into HIV nursing but how much she had enjoyed her career change.

Meet people on their own level
*I've worked in the NHS,
A long time now,
You've got to meet people on their own level.
The actual background of HIV,
The risks that go with it ,
And all of that,
I've learnt a lot around issues of prejudices.*

4.1.10 Iona

Iona seemed quite shy, and was very formal in manner. Her posture was slightly apologetic and she appeared awkward at times. Iona kept insisting how much she liked to talk and spoke very quietly and laughed nervously, when given the opportunity to tell me stories from her practice.

Iona came into nursing via a very different route than others I interviewed. Initially, Iona was a researcher in pharmacology. She appeared very intelligent and passionate about this area of care. She had gone to great lengths to train as a nurse, which then led her to pursue a job within HIV care.

Iona was the participant I was most surprised by, as the experiences she shared with me were at times unexpected and very enlightening. By the end of the interview, I got a strong sense of the kind of person Iona was. She had changed dramatically from the start of the interview.

A chance meeting
*I used to work at the university
HIV pharmacology research associate,
my official title,
the service changed,
I was doing a lot of research
it got turned into a service
it got to a point
I was making my mind up
whether to stay
I chose to do something different
went off
to do my nurse training.
it was just a chance meeting
with a consultant
I used to work with
in the street,
who had a job
HIV research nurse's job
he asked if I'd like to apply
I did
I ended up with the job.*

Having introduced the research participants, I will share with you another reflection of providing care for Joe.

4.2 Can You Show Me How To Be

During Joe's last admission to hospital I received a message from him to inform me that he was being admitted to hospital. By the time that I had got the message and reached the ward Joe was more stable, his breathing had started to improve and he was being treated for *Pneumocystis carni pneumonia (PCP)*. Joe responded well to treatment and a couple of days later I received another message from him: 'Croston, are you coming out?' Joe had advanced HIV and HIV related dementia as a result of years of not taking antiretroviral therapy. HIV dementia is no different to other forms of dementia in that it is characterized by regressive behaviour, resulting in patients having good days and bad days. I had become used to receiving messages like this from Joe and had wondered from his behaviour and spending time with him whether he had regressed to his teenage years.

I went to his room and knocked on his door.

Joe: You may enter.

As I enter I see Joe has made the room his own and surrounded himself with his home comforts: laptop, and enough chocolate, crisps and coca cola to supply the hospital shop. Next to Joe's tuck shop was a stack of CDs from the 80s and 90s, and multiple box sets of old TV programs from the same era, *Rent-a-Ghost*, *Grange Hill*, *Marmalade Atkinson*, to name but a few. Walking into Joe's room was like stepping back in time to my own teenage years.

Joe: Croston. Have you come to take me for some fresh air?

Me: Yes m'lord, I have, are you ready to go?

Joe had bought himself a Lordship, which consisted of a small piece of land in Scotland which, as a result, entitled him to call himself 'Lord'. He had bought this off

Groupon (an internet website that offers between 50-90% off deals of the day), along with a sonic screwdriver and light sabre. Joe was a huge fan of both *Star Wars* and *Doctor Who* and stated that he could not decide whether he was a time lord or Jedi warrior, so had decided to invest in both items. On bad days when Joe was grumpy and in a mood, he would yell at the staff to send me to the dungeons or the tower as a punishment for crimes to his lordship. Once, when his dad was visiting, he pointed at me and then commanded 'off with her head', which led to fits of laughter from his dad and a very serious looking Joe. On numerous occasions, Joe informed me that he was trying to pass a law that would enable him to do just that, behead people on command.

Joe: I am a little smacked up on this morphine at the minute and am walking like a tranny in a trance.

I couldn't stop myself from giggling

Me: Shall I get a chair?

Joe: Behave, I will walk, give me a second

Joe was tall and very thin, he had advanced HIV and looked like media images from the early days of the HIV epidemic.

Once outside we sat on a bench and Joe began to bring me up to speed with what had been happening with him during this admission. Then all of a sudden he turned to me:

Joe: What do you want to talk about? Before I had a chance to answer he began singing, "Let's talk about sex baby, let's talk about all the good things all the bad things that may be"

Initially I didn't know where the conversation was going but soon realized and began joining in with Joe's singing "Let's talk about you and me, let's talk about sex":

Me: Oh who sang that now?

Joe: (stops mid chorus) ‘ Salt and Pepper ... drrrh. Hey do you remember Five Star?

Me: Course I do and possibly the dance too

Within seconds we are both singing along to Five Star’s ‘Rain or Shine’. For the next half-an-hour we sat on the bench outside the hospital singing various songs that we remember from our teenage years. As we remember our favourite groups, songs and dance moves, we also shared stories that the songs had created for us. From nowhere lyrics would come to mind and we would sing along with each other laughing at how well we had remembered the words to the songs.

We were both busy singing along to Wham’s ‘Young Guns’ when Joe stops mid-song.

Joe: ‘Chelle that guy over there keeps looking at us.... He’s probably wondering what you’re doing with someone like me.

I turn to look at where Joe had indicated and sure enough one of the porters was smiling and looking our way. I turn away quickly, almost like I have been caught by a grown up. Not sure what to say, I respond quickly, almost without thinking:

Me: Narrgh. He is looking over and seeing what a great time we are having and wishes he was here as well.

On reflection I am not sure if I should have explored that further or tried to unpick what Joe was trying to say. Instead I chose to dismiss it. Maybe it was a conversation I didn’t know how to respond to.

This seemed to distract Joe long enough for him to begin telling me about the music collection that he had been buying from eBay.

Joe: You should see the amount of Greatest Hits that I have bought. If you come back to my room then I can play some of the classics. Eh if you get some weed we can have a real party.

I begin to laugh.

Me: Seriously do I look like someone who has weed?

Joe: Good point. You're a geek, I almost forgot that.

We both laugh and begin getting up to go back on to the ward. Joe stands up and sits down quickly. I respond almost instantly and move close by his side, steadying him as he sits back down.

Me: Are you ok?

Joe: Just a bit wobbly on my feet, a little weak ... Will I get to heaven?

These words came out of the blue. I was shocked and taken aback, so much so I physically sit on the bench and hold my breath. It felt like I had been punched in my stomach, which had left me unable to speak. What would I say, even if I could find my voice? Fortunately, I didn't have to respond just yet, the silence allowed Joe to expand on his question.

Joe: My dad said that I won't get to go and be with my mum in heaven, because I am too evil and I won't get in, that I am committing suicide and my dad thinks my mum won't accept me in heaven ... What do you think?.

I had so many thoughts running through my head. In my head I was screaming "WHAT, WHY WOULD HE SAY SOMETHING LIKE THAT?" I had met Joe's dad on numerous occasions and whilst he was not overtly a loving man, it was clear from his tireless support that he cared deeply for Joe. I didn't have a chance to respond as Joe had used the silence to think and then respond.

Joe: I think I have done enough good things to get in, this was my fault, I get that, I caused this infection, no one else, my choices ... But on the whole I am a good person.

As I listened to Joe, inside I was crying. So much self-stigma, so much pain. If only he could just see that HIV didn't have to define him, that he was more than his diagnosis. I put my arm round him and gave him a gentle hug

Me: You are a good person, an amazing person, HIV does not define who you are, I can't imagine you won't have a place with your mum.

That seemed to be enough for Joe. Maybe it was too much for him to process. He would often change the subject if one of our conversations got too deep for him.

Joe: Come on then Croston, let's go back to the ward and listen to some tunes.

I'm sure I'm due some more morphine. Eh do you think that guy that is gawping at us will have any weed

Joe laughs in his mischievous way and we both smile and head to the ward.

On the drive home from work I can't help but think about my conversation with Joe. His cognitive impairment and his raw emotional states often made communicating with him tricky. I am always very mindful of how vulnerable he is, and how intelligent and quick-witted he can be. His wit could be toxic, if you are on the wrong side of him. Joe had a reputation amongst the nursing staff for being a 'difficult patient'. Sadly, they could not see when labelling him that he was a patient having a very difficult time. Fortunately, I have clinical supervision the next day so I can explore my concerns there.

During my supervision, I begin to worry as I explain the story and the context in which it had happened. What was the porter thinking? Was he looking over and

questioning my professionalism, singing and dancing alongside Joe? What would my peers think? Had I blurred the line between professionalism and friendship? There were many questions to explore that made me feel vulnerable.

Should I have explored his dad's statement and the impact that had on Joe? Should I have explored why Joe felt getting this infection was his fault? Maybe after my supervision, I might feel better prepared to enter a conversation of that nature. Joe's fluctuating cognitive state makes exploring issues of this nature in any depth problematic and often extremely traumatic for him.

Joe is in a very difficult place, facing death and coming to the end of a very long, emotional journey. It seemed that all I could do was to be alongside him and support him the best way that I could.

When in front of my peers and medical colleagues, I can choose to hide behind the psychological standards and state that I was providing level 2 psychological support for Joe (which, in a sense, I was) which stated that emotional and psychological support is fundamental to patient care. Or, I can be honest with myself, and say it was me and my humanity sat on the bench with Joe, singing and dancing, not a set of standards and guidelines. There was nothing consciously guiding me that day. Just me, giving Joe time and space to be himself. In doing so, I was also just being myself.

Was our discussion therapeutic? Did I explore Joe's concerns using an appropriate model or mode? How can this be measured? What would Florence Nightingale say about my style? What would she think of how I chose to respond to Joe's question about him getting into heaven? Perhaps I should read her notes on nursing again, in particular the section of her writings "chattering hopes and advices". In this section,

Nightingale advises on “what to say and what not to say when in the presence of patients, paying particular attention to what may or may not be helpful” (Nightingale, 1860)

Chapter 5: Findings

When I first began my research I thought that it would centre around the development of communication skills and how such communication skills helped to elicit patients' concerns in order for nurses to provide patient-centered care. I soon realized that it was more concerned with nurses' way of being, how that way of being was developed through their own experiences and the therapeutic relationship that developed as a result of these factors. In addition to this, factors that were interwoven within the nurses way of being and the development of the therapeutic relationship, such as stigma and non judgmental care, needed to be considered, when exploring how nurses elicit patients' concerns.

In order to explore this wide agenda further I returned to my study's objectives which were:

- To explore HIV nurses' stories about clinical practice.
- To explore the therapeutic relationship that develops between the HIV nurse and patient.
- To analyse nurses' way of being when developing therapeutic relationships.
- To explore, through the use of stories, situations in which nurses have dealt with the emotions of patients with complex needs.
- To develop a way of thinking which contributes to the existing body of knowledge in relation to therapeutic relationships in HIV care, through the elicitation of patients' concerns.

With the aims in mind an inductive approach to analysis being adopted the following themes emerged, a way of being: HIV nurses experiences, the nurse patient relationship; and factors that impact on authentic care.

5.1 A Way of Being: HIV Nurses' Experiences

Throughout nursing history the importance of the therapeutic relationship has been

talked about. In order for a relationship to develop the nurse needs to find a way to 'relate' to the patient. Throughout my nurse training, and as I have developed my craft to the point of becoming a specialist nurse, great emphasis has always been placed on the therapeutic relationship that exists between the nurse and patient. This therapeutic relationship helps with the nurses' ability to elicit patients' concerns. Less emphasis has been placed on the nurse's way of being that enables the development of the therapeutic relationship. As a result of reflecting on my relationship with Joe and how I elicited his concerns, I began to see how my way of being had developed and led to more authentic care being provided, not only for Joe, but for other patients that followed.

When I refer to my practice as being authentic, I acknowledge Heidegger's thoughts which state that it is not possible for us to be authentic all of the time and that being inauthentic is also acceptable. What I mean when I state that I am being 'authentic' in the care that I provide, or that participants are providing, is that care is being delivered in a way that enables the therapeutic relationship to develop based on mutual respect enabling a partnership approach to care delivery. Reading through the transcripts I was interested to see if this had been evident within the participants' accounts when they were sharing their own patient stories from clinical practice.

The nurse's way of being was talked about within the patient stories and provided a lens to explore how the therapeutic relationship was developed and concerns were elicited. Through the stories that they share I got a sense of their way of being and the effect this has on the therapeutic relationship. A way of being appeared to be a significant theme when exploring the participants' narratives.

Within Harry's interview he talks about his thoughts and beliefs in relation to being a HIV specialist nurse and the influences that this has on the nurse patient relationship:

I think it is a privilege when someone comes to you with HIV or not HIV and are comfortable around you and I think that's a skill that as HIV nurses we need to be more proud of sometimes. It's not easy and I think sometimes people think, "oh HIV nurses you just give them medicines and hold their hands and stuff," but actually the skill is in just being with somebody and accepting them.

Harry acknowledges the privileged position he holds as a HIV nurse. The idea of 'just being with someone' is very clear within the extract and the apparent ease with which Harry is able to do this also seems clear. 'Just being' suggests an element of effortlessness on Harry's part, that this process is natural for him when eliciting patients' concerns. This supports my own inner beliefs. I am proud of what I do and feel in a privileged position when patients share their inner thoughts and concerns with me. Like Harry, I also believe people think it is easy to do what we do as HIV nurses, but the act of just being with someone and accepting them for who they are can be very challenging. As Harry suggests, it is a skill. I wonder whether it is a skill that can be taught? Would a way of being be more appropriate to describe Harry's approach to eliciting patients' concerns and providing patient care?

I am sure that providing care in this way is a challenge for everybody, not just for HIV nurses. When dealing with people living with HIV, nurses may have to question or explore some of their own beliefs around certain issues such as prostitution, homosexuality, sex and death. This can, in turn, affect the nurse's ability to be non-judgmental with the patient, which might influence the care given.

Harry goes on to explain his concept further by saying 'just to be with someone and make them not feel judged.' By using the word 'just' Harry devalues a very important skill that is fundamental to Harry's ability to elicit patients' concerns, his ability to be with someone and refrain from judging him or her. Harry takes this one step further and likens this approach as a benchmark to have with patients, with an overall emphasis being 'to be' with someone. When discussing the care that Harry is

delivering he likens his approach and way of being to that of presencing. The ability to be present so that care could be delivered. Heidegger used the term *Awesen* (presence) as a way to describe what is present (*Awesende*). Therefore, for Heidegger being as presencing means 'enduring in unconditional disclosure' (Heidegger, 1926/62:75). Within this context Joe's way of being present enabled the patients to disclose their concerns.

Throughout Erin's interview she appeared relaxed and keen to provide an honest account of how she provided care. Erin describes her way of being with patients and eliciting their concerns as being not 'very touchy feely' but acknowledges her way of being as being helpful:

I think from a personal point of view I think my way, much as I'm not a touchy-feely kind of person, I think my other way is helpful...I recognise we all bring different things to the table and we're all valid and important.

When Erin said her 'other way' I interpreted that to be an approach that was not very tactile. She later goes on to expand on her way of being to elicit patients' concerns, stating that it is more relaxed and jokey with patients.

Erin acknowledges the unique nature and individualized practice of nursing by suggesting that people bring different things to the table, acknowledging that we all offer a particular way of being for patients that helps elicit their concerns.

Within Erin's narrative account she gives an indication of her personality and light hearted approach to the nurse patient relationship:

I kind of just backfill with little silly jokes, but not inappropriate

When listening to Erin's narrative account and her use of humour within the nurse-patient relationship, I wondered if this humor was used in a way to try and make the

patient feel at ease, and not judged. This could also be Erin using humour to make herself feel more confident when dealing with such a stressful situation. I also thought of times where both patients and myself had used humour to diffuse very emotionally intense situations. Within this narrative account Erin used the concept of presencing in order to use her authentic way of being, i.e her use of humour to demonstrate that she was present, so that patients could disclose their concerns to her. Part of me also worried, what the impact of using humour would be on a patient's ability to express their concerns. Would this style facilitate disclosure of concerns or in fact hinder them? Erin's ease at back filling with jokes and humour suggested a process that she uses, to be genuine with the care that she provides.

Erin goes on to expand on her way of being and how she uses this approach to relate to patients. In doing so, Erin describes what she believes empathy to be:

I'm very good at putting myself in someone else's shoes. I think I do it a bit too easy ... I almost feel like across the room, put myself with them and think how I would want someone to be with me

Erin's description of her way of being is very visual. Her description made me think of various different definitions of what empathy meant to people and in doing so could see Erin's empathic nature with patients.

Erin goes on to expand on the perceived downside to this approach:

Actually I think it is a good thing but it's quite draining really, because I can get very involved in my head. I do go away and it plays on my mind a little bit, you know about what they're really going through when they walk out the door.

Erin describes the emotional impact that her approach has on her and the feelings that she is left with afterwards as a result of being emotionally present with the patient. Erin suggests that she becomes overly involved within her head and these feelings stay with her long after the patient leaves. The long-term impact of this may be that Erin becomes emotionally distant from patients or becomes inauthentic to

protect herself, which in doing so affects her way of being with patients and ability to elicit their concerns. An alternative view of this could be that this process is what makes nursing meaningful. That, as nurses, we get to meet a variety of different people and share their experiences.

Shauna's way of being is highlighted when she is asked to describe her reasons for coming into HIV nursing. Within the extract Shauna's natural way of being is clearly demonstrated. Her suggestion of having a natural interest and empathy seems indicative of her approach to patient care when eliciting their concerns:

'It comes naturally to want to get alongside them and support them'

The idea of walking beside someone on their journey, really resonated with me.

Walking alongside them, as opposed to in their shoes, as Erin suggests, offers an alternative definition of empathy:

I think probably that I would have a natural interest or empathy for this particular cohort of patients. I suppose that gives me naturally um a desire to want to care for them. So I suppose in that way I'd want to look after them, so it comes more naturally to want to get alongside them or support them, or you know, spur them on in different ways.

'spur them on' is an interesting concept and reminded me very much of a coaching style to care. Being on the sidelines, involved, yet watching, shouting words of encouragement as the patient carried on.

Shauna's alternative definition of empathy also illuminates Heidegger's thoughts on Dasein being present. Heidegger suggests that Dasein being present has very little to do with objective space. The idea that you do not have to be physically present in order for care to be demonstrated. Even if someone is not in your physical sight, they can be present with you in mind.

Louis summarizes what he feels are the essential components within the nurse-patient relationship. In doing so Louis gives insight into his way of being when eliciting patients' concerns. Louis refers to his way of being within the nurse-patient

relationship as 'just being with the person, just being close by'. These words suggest a natural, unforced style, a way of being, and a natural state with the reassurance of 'being close by'.

Within this extract 'being' is referred to on numerous occasions. Whilst listening to Louis' interview over and over again and analyzing the transcript, it felt as if Louis was trying to describe a natural state and was articulating a concept of what made up his way of being within the nurse-patient relationship. The frequent pauses within this account may indicate Louis was thinking about his words carefully as he began to articulate what he felt was important within the nurse-patient relationship:

Giving time and being. When possible not being interrupted. When you can be available and think mainly those things, actually listening, being .. just being with the person .. just being close by

Louis way of being within the therapeutic relationship, also compliments and links to Shauna's alternative definition of empathy and the subsequent notion of being as present.

When exploring the nurse-patient relationship and way of being in order to elicit patients' concerns. Iona offers the following interpretation:

I think you need to just say 'see how you go'. I'm not saying they can get the information better than me but is your approach different than my approach and personality wise, experience wise you might be better able to deal with that person than I am.

Suggesting her style is free flowing, Iona recognizes that other healthcare professionals may be able to facilitate disclosure of concerns differently based on their way of being. Within the narrative account Iona acknowledges the unique qualities that make up the nurse and the impact that this has on establishing concerns. Personality is offered as a way of being, along with experience, both being facilitative skills and restrictive when establishing patients' concerns. Within her

account Iona is also comparing her skillset with others and wonders if other people's approaches may enable disclosure of concerns.

In her narrative account Holly describes the privileged position she feels within the nurse patient relationship and in doing so gives insight into her way of being when eliciting patients' concerns:

I mean the reason that I like sexual health are the reasons that you get to. ...talk about quite intimate problems with patients and you get a lot of erm ... you get a lot of erm patients that come to you and talk about things that they have never spoken to anybody else about ... and that's a real privilege in lots of ways

Within this extract Holly mentions that patients may disclose things that they have never spoken to anyone else about. There is an inference that Holly's natural way of being with patients allows this intimate disclosure of concerns to take place.

When this concept was explored further with Holly she goes on to suggest that her ability to elicit patient concerns was based on her personality and natural way of being. This seems similar to Iona's acknowledgement of different personalities being able to deal with different patient situations:

I think its part of my personality, if you like, to be like that

The idea of personality links well with the concept of historicity and the importance of this in the development of therapeutic relationships that facilitate the disclosure of concerns. This acknowledges that the nurse's own historicity has a direct impact on the therapeutic relationship and their subsequent ability to elicit patients' concerns.

Zayn also explores something Holly had mentioned within her narrative account:

a lot of patients have not told anybody about their HIV at all, so just to be able to talk to somebody about it is a massive relief in itself, because there is no fear

there about where this information is going to go. They can talk to us openly. A lot of patients do say that we know more about them than any of their relatives or family know because to them they've got this little secret that they can't talk about, and so to be able to talk to us about it, is a massive relief for them

Within the extract I get a sense of Zayn's way of being as very relaxed with an accepting manner that enables patients to confide very personal information. Zayn's narrative account and way of being made me view the nurse-patient relationship as being akin to a safe haven, a place where the patient is able to be open and free from secrecy. This links back to my pre understandings that the nurse provides sanctuary for HIV patients.

Listening to the participants' stories from practice made me consider the importance of the nurses' historicity in developing their way of being in order to elicit patients concerns. The sense of historicity and nurse patient experiences appeared to be a strong theme that influenced not only the nurses way of being but the therapeutic relationship that developed and the nurses' awareness of factors that comprised authentic care or inauthentic care depending on the nurse's historicity.

Within Orla's interview she shares a story from her nurse training where she had spent time with a female patient who did not have any visitors. Despite other members of the team considering this not to be her role, Orla firmly believed that it was part of providing care to someone. I asked Orla how she felt she had developed these skills, if they were skills she had always had or something that had developed throughout her career. This led Orla to share the following:

I think I've always had a caring side and even going back to Junior School (umm, laughs) I came out of school, I think I was about seven with no vest on because my friend had holes in hers so I gave her mine (laughs). So I think I've always had a caring side, but you know, I do think that (umm) I have always been able to talk to people.

The extract describes a childhood experience, which indicates Orla's natural way of being. The extract also indicates (with Orla's admission of giving her friend her vest) that she has a natural caring nature. This caring nature puts the needs of others first which has facilitated the development of a natural way of being able to communicate with people. This invariably will be translated into her nursing practice that helps her to elicit patients' concerns. The narrative also highlights how historicity has influenced the care that Orla provides, that her past experiences, influence her current practices.

Shauna explores where she feels she may have developed her ability to practice patient care in the way she does, suggesting her historicity plays an important role in this process:

I think my own lived experience, in just knowing about difficult times in my own life enables me to have more empathy for other people.

Shauna clearly identifies her own experiences as being influential in her way of being with patients when eliciting patients' concerns. I also wondered if the difficult experience she was thinking about also helped her in developing her authentic approach. Shauna's use of her own experiences in order to provide care shows an example of the temporal nature of the caring relationship, in that the past influences the present and future care.

I wanted to ask Shauna if these experiences had helped in developing her authentic approach. However I felt, it would have been too intrusive to ask. I thought that by asking, I would cross some line, a line that I had imposed to protect her or me. As I think about this section of the interview, I wonder if my lack of probing was more to do with being an inexperienced researcher or based more in fear of what she might have said. I liked and admired Shauna. I also use my own experiences of difficult

times to demonstrate my empathy, experiences that I would not want to share in an interview setting. On some level I assumed I understood what life experiences Shauna was referring to, based on my own experiences. I wish now I had asked instead of assuming. I should have asked instead of being concerned that she would view my probing to reach a different level of understanding as that of me being nosey.

Iona also talked about her childhood experiences and how they helped to shape her ability to communicate and develop therapeutic relationships. Within the extract she jokes about her ability to gather information from people as being developed as a result of arguing with her sister. Iona admits to being very shy as a child and was never confident in speaking. In an attempt to overcome this her dad encouraged her to speak at the dinner table about a subject of her choice. It is clear from the extract that her family experiences were influential in helping to shape her way of being that helps to elicit patients' concerns:

arguing with my sisters (laughs), probably was helpful in trying to get things out of other people (laughs). I was brought up a Catholic and went to church every Sunday .To improve our communication skills, on Sunday afternoons when we were together my dad use to pick on one of us and we used to have to stand up and give a minute's talk on a subject or an experience (laughs).

Within the extract Iona demonstrates the importance of historicity and temporality, how her childhood experiences have helped her to develop a communication style.

Reading Iona's extract, I wondered how significant her Catholic faith was on the development of her way of being. Catholicism has some very fixed views on homosexuality and I wondered how much these beliefs had impacted on Iona growing up. I wanted to ask more about her religion and the impact this had on shaping her way of being. I wanted to know whether she still went to church and how much Catholicism was still part of her life. Was this something that she had moved away from as she began working in HIV care or had her work strengthened her faith?

I didn't act on my thoughts. I am not sure why. I now wish I had asked Iona more questions about this disclosure. On reflection, whilst I was gathering my data, I didn't realize the significance of the nurses' experiences in shaping their way of being.

I was really pleased when Louis agreed to be interviewed as Louis had worked in HIV care since the start of the epidemic. I felt that this would shape his way of being when eliciting patients' concerns, as he brought not only his own historicity to the interview but also the historicity of the HIV disease itself. During his interview he recalled stories from the start of the HIV epidemic:

I can tell you about a patient who. Who was in the ward ... who had Kaposi sarcoma. The Kaposi sarcoma whether. I cannot remember whether it was being treated or not ... but the treatment wasn't working ...and the Kaposi's sarcoma was on his chest and basically.. this fella died as a consequence of drowning and mechanical obstruction .. not mechanical obstruction .. mechanical compromise of his breathing .. the weight of his lesions with the odema were so great that he eventually tired of breathing and that wasn't a good situation

Louis' horrific medical description made me consider how extremely difficult it was for Louis as a nurse providing care in that situation. I wonder whether Louis sticking to the facts of this situation served as a protective factor. During the interview he gave me the impression that this was not something I could explore further with him in the interview. Further in the interview I returned back to this patient story and asked him if there is anything that springs to mind when thinking of this patient situation. Louis responded by saying 'this is just a memory, a picture memory of someone suffering basically'. I think how distressing that picture memory must have been for him. I wish now that I had explored this further with him. Although I am not sure that he would have opened up to me at that point. Recently, I have had discussions with Louis separate from this interview where he talks about feeling burnt out and I sensed that this had happened many years ago, possibly around the same time as these incidents. There was a sense from Louis's narrative about the importance of

temporality when exploring how care is delivered. Louis's knowledge of HIV and experiences of providing care for patients as the disease area changed have all led to him developing his way of being when providing care.

Louis goes on to remember another patient and shared the following.

I can vivid ... Vividly recall taking a patient home and that was before, that was when I was working on the wards ... so that was off duty ... talk about lone worker policy ... this was a young women ... Who was a scientist who had developed cryptococcal diarrhea and she had ... diarrhea in a cubicle. The common thing that it was then...30 – 40 times a day and I remember ...I remember driving her home and ...never seeing her again

When Louis talks about the scientist, it is clear that there is more emotion attached to this memory as he states that he can vividly remember. Louis also indicates that he went out of his way for this lady. Louis later questions whether this was safe to do, and refers to the lone worker policy which cautions against this. For me this indicated how Louis's way of being had changed over time. There appears to be a shift from protecting the patient, seeing that she gets home safely, to protecting himself with the lone workers policy, which ensures workers get back safely.

There was a sense of loss for Louis as he stated that he did not see her again. I wonder whether driving her home with his HIV knowledge, he would have known that this would have been the last time he saw her. These experiences give insight into how Louis' way of being has developed and as a result shapes future interactions with patients. This links to the concept of temporality, indicating that the past always has an impact on the current situation.

Similar to Louis, Harry recalls a distressing patient story in relation to a patient dying as a result of his late diagnosis:

I had a patient when I was working on the wards, he was a young gay man who came in who was very unwell, he had a partner neither of them had been tested for HIV when he came in. He was unwell and (umm) we did HIV test on

him which we do as routine on the wards, and it came back positive, and I remember having a conversation with him afterwards and he basically said that he'd kind of buried his head in the sand for a number of years, and he and his partner had never really spoken about it and just kind of trundled along and he'd become generally unwell, but never thought to have a test. His partner was really supportive and his Mum came in and was really supportive and he had PCP up in high care and had become really unwell and confused, and I think I was on quite a lot that week when he was in and he ended up going into ITU and he died and he was only (well I was probably only about 23, 24 or 25 at the time) and he was a bit older than me, probably as old as I am now, about 31 and I remember thinking, I don't know, it was very difficult because he was so young.

Harry goes on to reflect on the patient's story and the impact this had on him, including the feelings he had as a result of his patient experience:

it shouldn't have happened and he knew that as well and his partner knew that. I mean it always sticks with me, so I remember he (umm) transferred into ITU and he was quite out of it and was intubated and I went to visit his Mum on ITU when he wasn't well and he ended up dying and his partner came to visit him all the time and hopefully I provided them some support, but I'll never forget him and his partner because they were young gay men, like me I suppose, and I just thought, you know, this shouldn't happen.

Harry expressed very strong feelings in his reflection that this patient's death should not have happened. He stated that the patient and partner knew that they should have had a HIV test sooner, which ultimately made the experience hard for Harry to deal with. It was such an avoidable outcome. If he had taken a test sooner his death, and the impact of his death on his partner and mum, could have been avoided. There is a holistic feel to the care that Harry provided as it is clear that he supported everyone involved. Harry also went out of his way to provide this care as he visited them in ITU to continue to elicit their concerns and to provide emotional support. Harry's way of being can also be linked to that of presencing. Harry was not always physically present or responsible for providing care whilst the patient was in the ICU department. However, it is clear from the narrative account that the care that Harry demonstrated to the patient's family showed that he had kept them in mind.

Harry states 'I'll never forget him.' The reason being that he was similar to him as ' a young gay man'. This must have been extremely difficult for Harry emotionally and highlights the emotional impact of patients' stories on the nurse and how patients can influence nurses to develop their way of being. By Harry acknowledging that the patient was a young gay man like him, it further highlights how the nurses' experiences, in Harry's case his sexuality, shape their ability to provide authentic care. Based on Harry's sexuality he was able to internalize the experience and in doing so reach a deeper level of understanding with the patient. Harry's sexuality is a part of who he is and therefore helps shape his way of being.

In summary, throughout their interviews the participants highlighted how their different ways of being influenced the care that they provided and ability their to elicit patients' concerns. Shauna and Erin offer very different ways of being in order to provide authentic empathic care for patients. For Holly and Shauna their reasons for coming into HIV nursing were also very linked to their way of being. This links to Iona's suggestions that different nurses ways of being could influence the care that patients receive. These factors led me to consider the importance of nurses' experiences in developing their ways of being when considering how they elicit patients' concerns.

Within the extracts, Orla provides an account that suggests her way of being developed through childhood; suggesting that these experiences have enabled her to provide authentic care as a nurse. Shauna also acknowledges how experiences from her own personal life have helped shape her way of being and ability to provide more empathic care. Louis's early memories of providing care for patients at the start of the epidemic when prognosis was poor helped to shape his way of being and influences how he provides care. Similarly Harry's experiences of caring for a young gay man similar to himself impacted on his way of being. Harry states that he will

never forget this patient and in doing so the experience will continue to influence the care Harry provides. From the extracts it would suggest that the nurse's historicity and the experiences that have shaped this, influence the nurse-patient relationships that have been developed, enabling authentic care to be provided.

5.2 The Nurse Patient Relationship

Listening to the participants' accounts it became clear that the therapeutic relationship was developed as a result of the nurses' way of being which is influenced by historicity. Both factors then influenced the dynamic that occurred that led to authentic care. Therapeutic relationships became a strong theme throughout the transcript when exploring how nurses elicited patients' concerns. Through the patient stories that were shared, insight into the nurses' authentic practice can be seen.

As previously mentioned Harry offered his views on the nurse patient relationship suggesting it was a privilege to provide care alongside patients. This gave insight into his way of being and how he goes on to elicit patients' concerns. Harry takes this one step further and likens this approach to a benchmark to have with patients:

I think that in terms of dealing with people's concerns it's about starting off with a benchmark, your bottom line that you're not judging them about HIV. You might give them advice about their lifestyle in whatever capacity, say in their drinking, using drugs or you know getting them help professionally.

Harry acknowledges the importance of having a standard benchmark for skills, the bottom line being that you should not judge someone who is HIV positive. One of my mantras, which supports my pre-understandings, is that non-judgmental care is fundamental to HIV care. This also highlights the importance of temporality within the therapeutic relationship, that past actions can influence the present, which can potentially influence the care that is being received. Therefore, in order for authentic

care to be provided nurses need to be aware of the importance of being non-judgemental, as patients may have experienced judgemental care in the past.

The importance of just being with someone and being authentic is further explored in Shauna's extract as she recalls the impact that a patient had on her. Although Shauna did not remember the patient, it was clear that she had left a lasting impression on him. The patient recalled the way Shauna had treated him after he had received the distressing news that he was HIV positive, impacting on his sense of self and how he believed he should be treated. It would appear that Shauna's response had been very natural and empathic. Based on this encounter it suggests that Shauna is a naturally intuitive practitioner. The impact on Shauna was one of genuine surprise and shock. This was expressed by Shauna in the emotive 'aww wow aww' language that she uses, in particular:

oh I remember you from when I was newly diagnosed' and I actually hadn't. I remembered him and his name, and like vaguely remembered him, but I hadn't remembered everything around his diagnosis, but he got diagnosed on the ward, he was really poorly at the time. He said 'oh yeah when I was diagnosed, you came in and you put a drip up for me' and he said 'I'd just received the news that I was HIV positive' and he said 'I don't remember what you said, but I remember you sat down on the bed next to me and you held my hand and it was the way that you looked at me' and he said 'that really helped me to cope with that day'. And I thought aww, wow, aww! I was so pleased that I had stood out for him and it's like what you want as a nurse, that you want to be able to be there for people and it, yeah, it just stood out. It doesn't matter what words you choose or what you say, but the care that I showed him that day obviously came across, so yeah that stood out to me I think.

There is something quite powerful about the words '*The way in which you looked at me helped me cope with the day*' as they highlight the importance of being authentic with people. Shauna describes the process of being empathic with patients, and, in doing so, describes a core component eliciting concerns and providing care. Shauna highlights the importance of this patient's story as it confirmed to her how she wanted to be remembered, as being there for people. This links to the idea of intentionality

being there for someone, although at the time Shauna had not been aware of the significance of the care that she was giving. Through authentic presence caring communication occurred.

Reflecting on this experience, Shauna explained the impact that this patients' disclosure had on her:

It doesn't matter what words you choose or what you say, but the care that I showed him that day obviously came across, so yeah that stood out to me I think.

Throughout Shauna's narrative account it was clear that she had been taken back by the realization that being her authentic self had been recognized and validated by the patient.

Shauna 's intuition is again revealed later in the transcript when she is reflecting on the care that she had given to the patient and what had led her to these reflections, Shauna states 'I had the sense from him'. So nothing verbal or physical that alerted her to the fact that he wasn't doing well, she just sensed it.

Shauna further elaborates on how she identified her patient's concerns in this situation:

I think I noticed that he just wasn't himself. He was very down and so I think umm before I'd even started talking to him I had that sense from him, that something wasn't right.

The extract highlights the gut instinct Shauna uses in her care. Shauna stated that she had a sense from her patient that something was not quite right, suggesting a heightened intuition and emotional awareness. These factors enabled the therapeutic relationship to develop and subsequently concerns to be expressed. In doing so Shauna was able to provide authentic care and support the patient with their concerns.

Orla describes the way she approached a challenging patient in order to understand his concerns and provide him with the support he needed:

you know, sort of just not going in all guns blazing, you know just going in and sort of just being a friendly face to start with, and then just gradually you know, start asking questions, encouraging him to ask questions and just like a gradual sort of process, rather than going in and you know, "right, I'm you know, I'm the nurse and this is what you've got and this is how it is, and this is how it's going to be", and rather than like that just a sort of gently, gently, softly approach.

The process described, feels very natural and respectful as Orla suggests, as opposed to a quite aggressive approach. 'All guns blazing' conjured up, for me, an image of a nurse holding a gun to a patient and forcing the patient to talk, bombarding them with questions. Orla's way implies a more natural patient-centered approach which acknowledges the sensitive and almost fragile nature of human relationships.

Niamh affirms Orla's approach in her narrative account when she describes how she develops therapeutic relationships with patients:

What's the best or the best way to go about things. I think that comes from the experience and that's it sometimes you can't fix it at this point. That's not how you are in the beginning, I think at the beginning it's gung-ho, I'm going to help you and you're going to listen and everything will be fine, but you recognise as time goes on that isn't the way to do it and that's not what patients want and that's not what makes a success story for them.

Niamh's account also firmly places the patient at the centre of the interaction. You can see a shift within the account from an authoritarian 'fix it' perspective, to a best-for-the-patient approach. It would have been useful to explore what Niamh meant in relation to 'success story,' how she defines success and what were the key elements she felt patients want to include in their success stories. It is clear from the extract that the therapeutic relationship that Niamh develops enables the patient to be in control or author their own story, suggesting a very patient focused way of being when eliciting patients' concerns.

Iona talks about the outcomes of her interactions with a patient who had previously been unwell and was facing a palliative care referral if he did not begin to adhere to his treatment. Iona talks about the thoughts she has in relation to how the therapeutic relationship developed:

It was more holistic care because I could give him a cup of tea and have a chat. At first it was quite difficult to build up that relationship with him because he just used to come in, sit there and ask him questions. It was like playing the yes/no game and eventually he started to open up and I found out more about him, and then we actually got him to be undetected for the first time since he's been diagnosed quite some time ago.

Within the narrative account you can see a shift in the nurse patient relationship. At first, Iona describes the relationship referred to as being like 'playing the yes /no game'. This then shifts, with the patient opening up and Iona being able to find out more about him. Iona suggests that she wants to find out more about 'him', indicating that she is viewing him more holistically, interested in the person and not the disease. Iona's way of being with the patient enabled better health outcomes with the patient's disease taken under control and becoming 'undetectable'. This is a way of ensuring the HIV virus is controlled on treatment. If the viral load is undetectable then the virus cannot replicate and cause damage to the immune system. The shift described was clearly beneficial, not only to the patient, but to Iona herself. Iona was able to create a more authentic approach with the patient which then led to better health outcomes for the patient.

When asked to consider what experiences she felt were important in shaping the therapeutic relationship, Niamh shared the following thoughts:

I think a lot of people in some ways prefer an older person, you know they think oh well they're not judging me they've got a mother like figure or whatever, you find when you're older you can mix, I'm not saying when you're young you can't, but you can't mix with all different kind of clientele, you know things about you know their culture, their you know, their country and I think those types of

things come into play because you know before you start you've got an idea of where they may be coming from.

Niamh also highlights the importance of authentic practice. Physical maturity is also linked with emotional maturity, which Niamh believes enables patients to disclose concerns. Within the extract Niamh uses her own historicity in order to shape the therapeutic relationship. Niamh acknowledges the importance of temporality when eliciting patients' concerns.

Holly was also asked to consider what she felt was important in the nurse-patient relationship. Holly mentions the process of time and experience as being important.

Throughout Holly's extract patients expectations, and living up to these expectations appears to be present within the nurse-patient relationship, with Holly saying 'you know, you hope that you will live up to the expectations patients have'. This suggests that the nurse-patient relationship comes with an expectation of you, as a professional, having to be active within that relationship in order to 'Live up to' that expectation and that patients will be evaluating your performance as a nurse:

suppose it's just over time really and experience..... and what ...the expectations of what patients have and you know you hope that you live up to the expectations that patients have.

Harry considers his relationship with patients to be twofold, that of being a friend and also empowering patients to deal with their concerns. Harry describes his relationship with a patient in the following way:

You're a pal with patients ultimately aren't you and we like to see ourselves sometimes as helping people as problem solvers, but ultimately I think what we want to do is help patients solve their own problems and deal with their own concerns, not in a 'you can deal with it yourself' but in a 'let's give you some tools for you to be able to deal with it yourself.

The idea of being a pal with a patient initially seemed to go against the nurse patient boundaries. The idea of the nurse being a problem solver within the nurse-patient

relationship is also alluded to within the extract. Harry goes on to describe the empowerment gained through enabling patients to solve their own problems. Harry's account alluded to the idea that he views this process as being part of his role. I wondered if Holly felt that she always needed to act in a certain way to meet approval from patients, and if she did how this would impact on her ability to be authentic in the nurse-patient relationship when eliciting patients' concerns.

Harry expands on this by saying:

the greatest thing you can do in terms of getting people's concerns out is for them to feel that they are able to then do something about them themselves.

Within Harry's narrative account it is clear that he sees his role as being to empower patients. There is a sense that he has gone from being a fixer to facilitating how these concerns should be addressed for patients to reach an outcome. This concept supports my pre-understanding that patient-centered care facilitates empowerment.

When asked to consider the therapeutic relationship that had developed with patients, Zayn reflected on an incident that happened within his practice when providing care of a newly diagnosed patient. Zayn highlights the multiple dilemmas this patient story had on him.

Within this extract Zayn talks about a dilemma from clinical practice where he was forced into a position to give a patient their HIV diagnosis on Christmas eve. Through the extract you can see how challenging this situation is for Zayn. From the beginning of the story he states that this was a mistake made by another nurse, who did not offer the patient post exposure prophylaxis (PEP). PEP is HIV medication that could potentially prevent the patient then developing HIV. PEP is similar to emergency contraception and needs to be given within a certain time frame (up to 72 hours) in order for it to be effective.

Zayn weighs up the advantages and disadvantages of giving the result to the patient on Christmas eve, highlighting the challenges of providing patient-centered care versus protecting the rest of the population. Throughout the extract it is clear that this has been a very challenging dilemma, as Zayn concludes by stating: 'still in my mind, I don't know whether we did the right thing.'

one that sticks out in my mind, and I don't know why was a young lad who was 19 at the time and we had to give him a new HIV diagnosis on Christmas Eve, and this guy has got a lot of other issues going on, erm we'd known him a few times, but I think the reason it sticks out is that it was a mess up from another nurse who was working here at the time when he came in two days after having erm unprotected anal sex, was negative at that point, PEP was never discussed, then came back and was tested positive post...Now we don't know if PEP might not have worked and all those issues, but then it was because it was a long period and had to give him the HIV result over Christmas and things, and I think that was the difficult part of – I'm giving you this result now, but by the way we're all going off on leave for 4 days- or should have not been given the result and told him after Christmas, but then that would be no good on the 2 weeks period that we say your results were negative, then is he going to go out, have sex with somebody, we know he's probably sero-converted and he's probably going to put someone at risk. So it was that dilemma of do we look after the patient and tell him after Christmas or do we look after the greater population and tell him now. And still in my mind I don't know whether we did the right thing telling him on that day.

Realising that this was a very complex dilemma for Zayn, I empathised by saying that this sounded like he was trying to work out the best situation. Zayn suggested that the reason this is so memorable for him is that he feels that he has let the patient down in some way. I am very conscious of how Zayn feels that he is in some way responsible for this patient's inability to adjust to his diagnosis. Zayn clearly sees the magnitude of the diagnosis and feels he had let the patient down. I go on to explore this further within the interview by asking if he has ever voiced his thoughts to the patient. Zayn informed me that the patient has nothing but praise for the clinic and Zayn himself. It appeared that this information did not reassure Zayn, as he still appears distressed about the incident. From the patient's perspective Zayn's honest and authentic care enabled him to adjust to his HIV diagnosis. Despite Zayn's

concerns about how the situation was handled, the care provided by Zayn helped to protect the therapeutic relationship.

Zayn's account of his dilemma can also be linked to the concept of presencing.

Although Zayn was not physically present to provide care for the patient after his diagnosis, the authentic way in which Zayn demonstrated care within the therapeutic relationship may well have helped the patient adjust to his diagnosis.

Similar to Zayn, Shauna described the emotional dilemma of balancing patient care and protecting the wider population. Shauna enters into a long supportive discussion with a patient following a condom split. She describes the impact that this had on her and the, almost palpable distress, this caused to the patient.

Within the extract it is clear how upsetting this situation for the patient was, as Shauna emphasizes 'he was beside himself, he was distraught, riddled with guilt'. Shauna's language expressed the range of emotions she was feeling. After the incident, Shauna states that she felt 'burdened by the sadness of the situation', acknowledging that patient stories can stay with the nurse long after they have been told.

he was very distressed because he had umm he's umm slept with someone a couple of weeks ago umm, and umm and he hadn't told the person he was HIV positive umm and he'd used protection, but the condom had split, and he hadn't told anyone in two weeks and then told me. So it was quite distressing listening to him because he was so upset and he was just beside himself. He was distraught over what had happened and it had not been a very nice situation. Umm and then he was just riddled with guilt that he had been carrying round for two weeks. What should he do? He hadn't told the guy and obvious things, so I dealt with it and umm and told him he should inform the man, which he did umm, and umm I sat with him for a long time. We chatted for about an hour about it and I've followed him up since over it, but I felt, like I came away from him quite like upset myself or burdened by the sadness of the situation and what had gone on over the past couple of weeks, so yeah it took me a while to process it afterwards actually, because I was a bit like 'oh he was so upset' and I think I took on a bit of that distraughtness that he had.

Shauna goes on to describes the approach that she used within that situation, in order to help the patient reach a point where he felt able to tell the person that he had HIV.

I think that I tried to listen in a way that was empathetic, umm and not judgmental. I was very aware that he hadn't told anyone because he thought he was going to be judged and he felt very guilty. Umm, so I could tell he was looking at me to wait for a response and umm I tried to just listen very openly and hear the story that he obviously wanted to get off his chest. I think I tried not to butt in too much but to hear the whole story, and to allow him space to talk. Yeah, and umm then as he said various things, I think I tried to just pinpoint what are the key issues here and tried to err, ask him questions so that he could expand on each of those things. Umm and then towards the end of the conversation, um I then tried to steer him into what would be a good course of action to move forwards, but I was trying to be sensitive and continued showing empathy, so that I could steer him in a way that was positive and umm, and not in a way that made him feel judged, or go away feeling guilty. Yeah I wanted to show him that I was walking next to him and helping him to move forward, rather than like I was opposed to him or you know, a judgmental health professional. So I suppose I wanted to provide an atmosphere that was showing him that he was cared for and helping him to move forward.

Shauna's natural empathic nature is highlighted in her desire to want to walk next to him to show him that she is a non-judgmental health care professional, who is trying to help him move forward within this situation. It was important for Shauna to listen to the patient, hear his story and demonstrate that he was cared for, in order to elicit any concerns that he had.

The words 'off his chest' suggests off loading an issue, indicating that there was a burden for the patient to get rid of. The extract suggests that her role is not passive as in this situation she 'steers', suggesting a direction, as opposed to forcing the patient into a course of action. The extract suggests a sense of togetherness 'walking next to him' implying that she is not judging him and that they are trying to find a solution together. Shauna describes the therapeutic relationship in this instance as being akin to a partnership, working together to find a solution.

Orla talked about the challenges she faced in clinical practice when trying to develop a relationship with a newly diagnosed patient who appeared very disengaged. Orla describes how difficult it can be to build up relationships with patients who may not understand how the relationship could be beneficial Orla states ‘ you could, you know, be quite easily put off’ by trying to build up a relationship with challenging patients.

Within this extract Orla suggests that her intuition was the main motivating factor in trying to build up a relationship. Orla states: ‘I think reading between the lines, I realized that he was actually very scared’. Although the patient had not verbalized this to Orla, she somehow sensed this and continued to try and build up the therapeutic relationship in order to elicit his concerns. This reminded me of Shauna and her intuitive response to her patient’s story and the idea of intentionally being there in order for caring communication to occur and concerns to be elicited.

Orla believes that this approach has worked. As a result she feels she and her patient have a good relationship, where he feels comfortable phoning her for support. Orla’s intuition was also correct as there was something that the patient was struggling with, as he found it difficult to ‘face up to what was going on’ .The patient is now engaged in clinical psychology. This suggests that there were underlying psychological issues that required further support. It is hard to establish from the story what changed. An explanation could be that the process of time had helped the relationship develop, alongside Orla’s caring nature and desire to help.

It was a newly diagnosed white British lad, heterosexual, (umm) who I went in to introduce myself, and his response was “I don’t know why you’re here, you can bugger off!”, and I thought oh right, OK, that’s nice (laughs), so I just said “oh right, OK, no problem I’ll come back tomorrow” (laughs) and I went back the day after and he was still quite resistant, but I persevered and eventually we did manage a breakthrough in that, you know, I feel now that we’ve got a really good rapport going, but that was really challenging at the beginning. You could, you know, be quite easily put off going, but I think reading between the

lines I realised that, you know, he was actually very, very scared and he didn't want to face up to what was going on, and that was why he didn't want to talk to me, but now, you know, he talks to me, he rings me and he's actually engaged in clinical psychology as well.

Similar to Orla, Allannah describes the challenges she faced when trying to build a relationship with a patient with very complex needs. Within the story Allannah uses powerful statements: 'You have AIDS' and, 'You've got 12 months to live'. Both statements conjure up vivid images of illness, desperation at having progressed to AIDS and how desperate the situation had become for the patient, after being given 12 months to live.

There is a strong sense of desperation as Allannah recalls that she tried and tried to help this patient seek treatment. Despite promises from the patient that he was taking his treatment, his viral load remained detectable, which indicated that the virus was not being treated and as a result this would lead to the patient's death.

It would appear that as a result of Allannah's perseverance she finally got the message across. This resulted in a shift in behavior and a renewed commitment with the patient being able to adhere to treatment. Allannah refers to the patient receiving treatment 'religiously', emphasizing the strong ritualistic commitment the patient now has to treatment. Allannah acknowledges the emotional impact this had on her, confessing that this was the first time she had been in this situation. Which deeply upset her. Within this situation the historicity of HIV impacted on Allannah enabling her to use this information in the present to provide care for the patients. This indicates that Allannah's way of being within this situation used the concept of temporality, using past knowledge in a way to impact on current care. The patient's behaviour is described as being that of a 'slow suicide' which is alarming to read, and, is a very strong statement for Allannah to make in relation to the patients'

behaviour. Allannah concludes with a sense of hope, suggesting that she will keep her fingers crossed that he remains well:

The consultant called me in and basically gave him the news that you know you have AIDS and if you start to improve things here, well basically you've got 12 months to live, and that was quite, it was the first time for me to be in that situation. As it is, he's now decided because he has a history of non-compliance with his meds that's why his whole sort of viral load has come to be so bad, and you know, we tried and tried and tried and he kept promising us dearly that he was taking his meds and he wasn't but we've actually now finally after that got the message across and he has turned and he is on the up and has improvement and he comes in weekly, religiously. That was quite upsetting, because I'd got to know this lad well and you know, he's such a bubbly character and so lovely and you know it was quite the realization of come on, you know, what are you doing you know? Like he's been on some sort of slow suicide or something here, you know something going on, but anyway he's doing well, so fingers crossed.

In summary, Harry gives insight into his thoughts around how patients feeling comfortable around him enables the therapeutic relationship to develop, likening this process to being a skill which he has developed and in turn helps to make up his way of being in order to elicit patients' concerns. This way of being is authentic and enables patients to feel comfortable around him. Harry also emphasizes that being friendly with patients and empowering them to deal with their own concerns is an important aspect of the therapeutic relationship.

Shauna also describes the importance of being authentic when developing patient relationships. She suggests that it doesn't necessarily matter what you say to a patient when they are distressed, but that patients value authenticity and empathy, which then enables the therapeutic relationship to develop. Such developments then enables patients to feel confident, when disclosing their concerns. Iona describes a shift in her way of being, moving to a more holistic style in order to improve patient outcomes.

Orla and Niamh describe a respectful approach to developing the nurse-patient relationship. This approach allows the patient to feel comfortable and disclose concerns, as opposed to a materialistic, fixing style, that is not conducive to patients' needs being central within the nurse-patient relationship.

When asked to consider important aspects of the nurse patient relationship Niamh and Orla suggest maturity, trust, the process of time and experience as being essential components that contribute to the nurse-patient relationship. For Holly there was also a sense that the nurse-patient relationship came with an expectation that needed to be lived up to.

Zayn and Shauna describe the challenges of maintaining a therapeutic relationship and protecting the wider population. Holly similarly suggests that there is an active element in the nurse-patient relationship. Orla and Allannah highlight the challenges faced in developing a therapeutic relationship and how they overcame these challenges. In both incidences the nurses way of being with the patients facilitated the ability for these relationships to form.

Within all the extracts there is a clear sense of how the nurses' way of being influences the development of the therapeutic relationship, which in turn influences patient outcomes.

5.3 Factors that Impact on Authentic Care

Through the interviews I wanted to explore if there were any factors within this area of care that participants felt affected their ability to provide support for people living with HIV (PLHIV). I wanted to highlight factors that participants considered made

developing the therapeutic relationship more challenging. I wanted to explore the impact of stigma within the therapeutic relationship and how non-judgmental care was delivered by HIV nurses. When referring to the delivery of authentic care, I mean care that is being delivered in a way that enables the therapeutic relationship to develop and is based on mutual respect enabling a partnership approach to care delivery that facilitates the disclosure of patients' concerns.

I wanted to establish how participants felt providing care for PLHIV differed from providing care for patients without HIV. I was also keen to establish how all factors influenced the nurses way of being and the development of the nurse patient relationship, which then helped the nurse to elicit the patients' concerns.

From the outset Shauna identifies that she felt HIV patients were a unique cohort; and describes how this contributes to her developing the relationships with patients.

I think you have a complete range of varied patients and patients from all walks of life as well and so I think you need to learn to look after patients who can be, you know like one patient you have in at 9 o'clock could be completely different to the one you have in at half past 9.

This extract articulates the multifaceted nature of nursing care. Shauna identifies that patients are unique and varied. She goes on to suggest that patients come 'from all walks of life'. This extract also gives insight into Shauna's perspective of providing patient-centered care. Shauna identifies the responsive nature of care and the ability needed to provide care for people from different walks of life, which could be argued is the same for all nurses.

Allannah acknowledges that underlying a patient's diagnosis are idiosyncrasies that make the people individuals. Suggesting that adding the HIV diagnosis into the situation may compound issues for the patient.

Allannah views her role as supportive, keeping the patients anxieties from progressing. This is reflected when Allannah states that her job is to 'keep them with their feet on the ground'. This implies that she might have to keep her patients 'grounded'. There is a sense throughout the extract that she is encouraging patients not to let their illness discourage them from living their lives. There is an underlying suggestion from Allannah that she is here to help facilitate patients' care by stating 'let's watch this, do this, do that, do the other'. I interpreted this as meaning monitoring patients' CD4 count or blood results and the practical aspects of clinical consultations, such as physical and sexual health screens. Within this extract Allannah acknowledges how temporality influences the care that she provides. In order for her to continue to provide authentic care to patients, she uses what she already knows about the patient, their histories, which then facilitates the care Allannah is able to deliver in the present.

You get to know people, you know these people are just people who if they didn't have HIV they'd have their own little madness, their own little personalities no matter what, but obviously this is there as well, we get them through managing it, going through life with it and accepting it and getting on with it really, you know that's our role to just kind of keep them with their feet on the ground, going come on you know, don't let it stop you, let's watch this do this do that do the other, but carry on sort of thing,

When thinking about what makes HIV care unique Harry offers the following perspective, alluding to HIV being very medically focused, with regards to learning about medication, and the need to be aware of other more holistic aspects of care.

you learn about medications, you are armed with information to give to people, but also I think you learn about the issues the stigma, you learn about relationships, issues on top of just the health care and so when people come to you, they feel comfortable that you know what kinds of things they are going through and that you've had experience in helping other people who have been in a similar situation and you're not kind of getting well how does this relate to your HIV when they come to you and say, well I've fallen out with my partner or I've you know, cheated on my girlfriend or I've done this or whatever.

Within the extract you can sense the holistic nature of Harry's care, looking at the whole person and the impact his care has on the patient. There is a sense from

Harry that this is not a passive dynamic, as he is armed with knowledge and relevant information that patients may need from him.

The choice of the word 'armed' suggests that he is prepared for battle which in the context of this extract suggests that it would be on behalf of the patient, arming the patient with all the information they need.

Experience seemed key to Harry's ability to elicit patients' concerns and provide patient-centered care and suggested that he learnt a lot from his patients in order for them to feel comfortable with him. Harry acknowledges the multiple issues that patients may face and suggests that it is important not to dismiss these in order to focus on the HIV, implying a person focused view of care as opposed to a disease focus.

Orla's thoughts also reflect Harry's previous observation in relation to providing HIV care:

You start working with people with HIV you realise that you know there are lots of other issues besides the HIV, you know like the sort of immigration, you've got your housing, your benefits, children. There are lots of other issues that come with it (umm) and I think that's what drew me into it and it's when you're talking to your patients, you're not just talking to them about the HIV, you're talking about the whole situation because you know, if everything else isn't sorted out then that can have a detrimental affect on your HIV treatment and attending clinic appointments and things like that.

Similar to Harry's account Orla acknowledges the multiple complex issues that PLHIV face. She suggests that this is what led her to work in HIV care, the ability to focus on the disease and the person.

Orla also implies that if you do not sort 'everything else' out then it has a direct impact on treatment and clinic attendances.

HIV and stigma appear to be a central theme running through the participants' transcripts. Allannah articulates her perception of why she believes being diagnosed is particularly challenging for the patient and in doing so highlights the impact of stigma:

There isn't anything I don't think that nobody, there isn't anything I can think of that if you are frightened, you couldn't not tell a person, everything else you know people generally you know may not like it, but they would be quiet, OK I can talk to you about this, talk to you about that, I can disclose you know whatever, but with HIV it's the one thing that's a no-no because it's still out there. You are frightened because of the stigma around.

During the interview when Allannah first mentioned this I remember sitting there and smiling. She had conceptualized the challenges people face when they are diagnosed, and the feeling that they are unable to share their diagnosis, out of fear of rejection. It felt quite sad when reading Allannah's extract as I agreed with her and could not think of any other condition that people would be, too ashamed to seek support for. Reading Allannah's narrative also reminded me of the concept of temporality, the past always impacts on the current situation, therefore in order for Allannah to continue to provide care which facilitates the disclosure of concerns she needs to consider the past and the way in which HIV was stigmatised. These factors could potentially influence the therapeutic relationship and her ability to elicit patients' concerns.

Louis expanded on this further in his interview and highlights the challenges he faces when establishing the therapeutic relationship.

I think that possibly working with positive patients with it being a very stigmatized illness...with the patients often being marginalized ...with patients who to this day still...to this day remember the adverts that portrayed and with then their ... thoughts on HIV being constantly really forced to a negative by people dying.

Louis identifies that working with positive patients is compounded by patients being stigmatized and marginalized. Louis suggests that this stigma stems from images

people have in their head from previous advertising campaigns that portray HIV as a death sentence. Within his narrative Louis acknowledges the importance of the historicity that is associated with the disease and how this can impact on the nurses' ability to elicit patients' concerns.

Listening to Louis, I remember the very powerful early advertising campaigns of the tombstone images and 'AIDS don't die of ignorance'. When reading the transcript I can almost imagine Louis's finger pointing in an authoritarian manner when he repeats 'to this day'. Louis's extracts touches on patients' pre-perceptions about HIV and how the presence of this can make establishing patients' therapeutic relationships harder.

Niamh also makes reference, similar to Louis's comments, in relation to patients having misperceptions:

You don't want people sitting in life not functioning because nobody has bothered to speak to them properly about HIV, nobody's bothered to say anything about them as a person.

Niamh, unlike Louis, suggests that there is an active role for the nurse in this situation that the patient should be informed about HIV. This information allows the patient to live a full life, and prevents what she suggests as 'people sitting in life'. Whilst Niamh's suggestion appears ideal, it does distract from the issue that despite the nurses' efforts to encourage patients to live a full and active life, stigma still exists.

Within her interview Erin describes the impact that stigma has on a patient and how this acts as a barrier to her being able to develop a therapeutic relationship. Erin describes how she uses the concept of normal to establish a therapeutic relationship:

I'm thinking of one where it was, I think it was with a lady who kept coming to the clinic with her daughter but she won't come into the clinic for fear of being seen and she wears a headscarf and dark glasses, and it was quite a public thing where she was infected by somebody who was prosecuted and she found out through him being prosecuted that she could potentially be infected, and she was in her 50s and was very respectable, middle class, white British, very kind of normal kind of life and you know, down the Sainsburys' for Brussel sprouts and tea and coffee with the girls, but kind of not, I'm not trying to, not someone like you'd automatically think would be at risk and just because her ex-partner, who I don't think she thought there was any risk, and I could just, it was sort of how palpable it was for her actually just being there and having her daughter with her actually holding her together into the clinic room, and she did come to all of her appointments,

The description she gives is of a normal, maternal like figure. I wondered whether this person could have reminded her of someone from her personal life. She goes on to describe how 'palpable' it was for her to be there with her daughter, suggesting that she could sense strong emotions from the patient. I remember thinking at the time that 'palpable' was a very powerful appropriate word to use. I could sense how difficult the situation was for the patient with this one word. The notion of her daughter 'holding her together' suggests being there, supporting someone close to you and the emotions that would evoke in a bystander. The use of the headscarf, suggests a need for protection, as if she had a need to cover the entire incident.

Erin goes on to recall her experiences through caring for this patient and her daughter. 'I remember her first just looking at me, sort of really grateful that I was being normal with her'. This was very powerful to listen to, I could almost sense within this story the lady's daughter looking at Erin, thankful for her level of care.

Reading this story reinforced the concept of stigma and self stigma within HIV care. This story is important to me as I can almost imagine the woman entering the clinic from Erin's description. The fact that something so personal, intimate and devastating, such as HIV diagnosis, should be found out in such a public way, led to

the woman feeling that she needed to hide herself. This created a different way of being that she had after receiving her HIV diagnosis.

As a result of my empathic awareness to the woman in this situation, I could relate to the woman's daughter, which led to a very powerful image of her holding her mum together in an atmosphere that was palpable with fear, anxiety and distress.

she was a good attender but she wanted to literally be swept in and out there with a cloak over her.

The idea of a cloak being thrown over her in a protective way, along with the image of this lady already wearing glasses, reinforced her desire to not want to be seen or to disguise what was really happening.

I remember just looking at her daughter whilst she was talking and she sort of looked at me with like a look of like gratefulness, like you're not judging her. Because I'd say like Hi blah de blah and how did you get up here? I heard like the bridge was choc-a-block this morning as usual, you know like just normal kind of, and I remember her just looking at me sort of really grateful that I was being normal with her.

Whilst making sense of this narrative I wondered if 'normal' was being used to avoid dealing with what was happening. I could sense why the daughter might be grateful for Erin's approach which then led on to the development of a therapeutic relationship which enabled the eliciting of this patients' concerns.

Erin goes on to talk about the skills she used when supporting this patient that enabled the therapeutic relationship to develop:

My kind of skills I think that I use are to normalize everything and to really make it, like this is no big deal but without, not being dismissive, but like saying how to use comparisons with, it's like living with diabetes, it's chronic, it's manageable, you're well supported... I play the diabetes card quite a lot and how normal it is...

The word 'play' suggests a game with patients, somewhat trivializing what they are experiencing. 'The diabetic card' reminds me of *Top Trumps*, a game I used to play

as a child, in which different superheroes or cars would be awarded points for certain characteristics. The idea of the game was to try and beat your opponent by comparing scores for different characteristics in order to win the game. This evoked an image of a game of *Top Trumps* for illness, with diabetes holding the same number of points as HIV. However, I am unaware about the reality of the comparison. Although diabetes is also serious and potentially life threatening, HIV is a very stigmatizing illness and diabetes isn't. Treatment may have progressed yet society's perceptions have not. This idea is reinforced throughout this story as the patient feels the need to disguise herself to access care. The more I thought about that statement the more vexed I became. Diabetes is nothing like HIV. Whereas there is a need to normalize certain aspects of HIV care, it should not be at the expense of minimizing patients' concerns. This is in direct conflict with some of my pre-understandings in relation to patient-centered care.

I wondered whether when Erin was being 'normal' with people was she being authentic? Was Erin being inauthentic to maintain her relationship with the patient?

Within Erin's interview the concept of normal has been used to defuse a situation and provide comfort to a distressed mother and daughter. By exploring the concept of normal through Erin's account offers an alternative view of HIV care. Erin's account of what she felt the benefits of being 'normal' with a patient were enabled me to explore this aspect of HIV care.

The impact of stigma on patients is further explored when Zayn is asked to consider what made dealing with HIV positive patients more difficult. Zayn shared the following observation:

There's issues around disclosure and things like that and how you would feel in that situation, it's not as obviously as straight forward as asking about diabetes because there is that stigma attached to it isn't there? So you've got to be mindful of that I suppose and I guess that is one of the big issues that would

have changed the way we deal with patients with this stigma attached because it's not straight forward to deal with as other situations.

Zayn offers caution when approaching HIV positive patients in relation to disclosure, suggesting that it is not like other disease. This is due to the underlying stigma that goes with HIV. Which as previously mentioned linked to the diseases historicality. Interestingly Zayn compares HIV to diabetes stating that a diabetes diagnosis is more straight forward as it is a disease without the same level of stigma.

Zayn states stigma is 'one of the big issues' for people living with HIV, and that the healthcare professional must provide support for this. This is reflected in the scholarly literature at great length and will be expanded on further within the discussion section.

Later in Erin's interview she acknowledges the impact of stigma and how it impacts on patients, making it difficult for them to attend their hospital appointments:

I worry about people who say to me 'I hate coming into the hospital in case I'm seen by Joe at No 15 who asks me why I'm here'. It's almost like there's an horrendous guilt that they have to tell these people.

There is a sense of empathy and understanding within the extract. Erin feels for her patients, referring to their 'horrendous guilt' for not being able to disclose why they are at the hospital.

Erin goes on to identify with the challenges the patient faces and openly admits that psychologically she would also struggle with a HIV diagnosis. I wonder how therapeutic this identification with patients is? Would this be counter transference or is it being emotionally aware and empathetic?:

I kind of think if I was them and I'd been diagnosed, how would I feel, I think I would have all their issues, I would be psychologically and emotionally in quite

a bad place because it's things like the girls who say I'll never meet anybody now, because no-one's going to want me. It's all the fall out of that, I sometimes feel, unfortunately, isn't always fully addressed.

After reading Erin's statement about patients' concerns of not being able to find someone because of their diagnosis, I wonder whether she also believed this or agreed with their fears. What impact would this have acknowledging, or not acknowledging those thoughts? What affect might this have for the nurse-patient relationship?

Niamh offers her interpretation of what non-judgmental care means to her and how within her practice she facilitates this care:

it's about learning to adapt to people, to different people. Do you know what I mean and sitting back and giving them time, you know by accepting people, people as they are. They might not be how you would want to lead your life, but you're not there to judge them you're there to make the best you can for that patient and anyone else involved with them.

I liked this section of Niamh's interview and the idea of accepting people as they are, particularly the notion that we don't have the right to pass judgment on people for the way that they live their life.

When reading this extract I felt that this portrayed all the key elements of what providing non-judgmental care was. There was also the idea of not changing people and trying to help people make the best of the situation they are in, I could relate to these concepts. I also sensed from the interview with Niamh that this was a natural, authentic approach that Niamh used with patients.

Erin also reinforces Niamh's observations and states the following in relation to authentic care,

I'm not sitting in front of you and you're strange, trying to make things like you're being non-judgmental, you really are just that person. I think I actively try and do that.

Within Erin's extract she described what she considers to be her natural state with patients, and in doing so implies that she is not pretending to be non-judgmental. Erin stresses that when she is providing care for patients she is being natural with them and not judging them.

I was unsure what the inference was when Erin followed on from this by saying '*I think I actively try to do that*'. In one sense she is saying that this is her natural way with patients. However, she states that she is actively trying to do that, so how can this be a natural state for her? Could these attempts be misperceived by patients as Erin judging them? Or, is this Erin's way of ensuring that patients felt that she was authentic?

Allannah gives the following interpretation of authentic care, suggesting that it is not necessarily about the individual person providing care, and more about the place of care that is important for patients:

we are the only place they can come in and feel very open so often they'll come and say hey I've got this thing here or I've got that rash there, can you help me look. Then again you go back to well what do you do, you've got all the other, sometimes the consultant's great and will have a little look, but we say we're only you know we can only deal with so much, we've got to draw the line at some point

Allannah's comments supported my pre-understandings that, as HIV nurses or care providers, we provide a sanctuary for HIV patients and a place where they can feel safe to disclose their concerns, even if these concerns are personal or potentially embarrassing. Allannah alludes to this when she recalls being asked to look at a rash, suggesting it may be in an intimate position.

Allannah also accepts that there may be a limit to what HIV services can do for patients, stating that at some point a line may need to be drawn, to illustrate the

limitations of the service. This statement highlights the fact that HIV care still remains very bio-medically dominated.

The transcripts suggest that HIV nurses are aware of the potential affect of these issues and adapt their practice to ensure the impact of these issues are minimal in the care they provide for PLHIV. The impact of the stories that have been presented demonstrates that the nurses' way of being is often very challenging, and is an ethically difficult situation. The stories give insight into the world of the HIV nurse and the patient relationships that are formed.

In summary, my initial motivation for undertaking this research was to try and establish the skills that nurses used in order to elicit patients' concerns, with a view to incorporating these skills into a skills training course. As a result of undertaking this research it appears that the skills the nurses are using to elicit patients' concerns have not been taught in a classroom setting. The nurses' way of being and the historicity that the nurse brought to the therapeutic relationship was important in facilitating care for patients. There were a number of external factors highlighted by participants as influencing their ability to provide authentic care. All these factors collectively enable the HIV nurse to elicit patients' concerns.

In order to explore these concepts further the nurse-patient relationship was explored. From the findings it suggests that the nurse-patient relationship was paramount to the nurse being able to elicit and respond to patients' concerns. What appeared clear from the interviews was the individualised practice of nursing within HIV care, and the impact that stigma has on the nurse-patient relationship.

There was a strong sense from the interviews that it was vital for the nurse to be authentic within the nurse-patient relationship in order to facilitate disclosure of

concerns. The unique treatment of the HIV cohort, and the need to provide authentic care, were identified as being important factors that participants felt influenced their ability to provide support for PLHIV.

The stories that the participants choose to share throughout the interviews demonstrated the uniqueness of the nurse-patient relationship, alongside the challenges nurses face whilst providing patient-centred care. The stories also give insight into the world of the HIV nurse and what it means to provide patient care from the nurse's perspective.

CHAPTER 6: DISCUSSION

6.1: Introduction

As previously stated in Chapter 1, I began this research to explore how nurses elicit patients' concerns. This interest was sparked by a series of practice based observations and reflections on my own clinical practice. Over a period of time, as a result of engaging in this reflexive process, a change in thinking occurred with regards to what nursing meant to me and how I wanted to provide nursing care. This change in thinking is highlighted in the reflections I have shared and is based on my experiences of providing nursing care for Joe.

In order to aid my thinking I consulted the literature on patient-centred care (PCC) as presented in Chapter 2. Within the literature it was suggested that although there was no consensus with regards to what the term patient centred care means, PCC is still considered an essential component of health-care. With regards to providing care, it was suggested that a positive therapeutic relationship was a necessary prerequisite for successful patient outcomes. The literature relating to HIV stigma and the concept of authenticity was also presented within Chapter 2. This enabled the discussion of therapeutic relationships and PCC viewed through a theoretical lens.

Within HIV nursing the way in which nurses provide care to PLHIV has been the subject of numerous studies and reviews. These studies highlight that the stigma and discrimination this group of patients experience is recognized as a global problem. PLHIV are often "perceived as dangerous and largely to blame for their condition"(Hodgson 2006:284), which can influence the nurse-patient relationship. There appeared to be a lack of exploration within the literature in relation to the positive aspect of the nurse-patient relationships that were developed when caring

for PLHIV. I hoped my research would help to offer insight into this area of nursing practice.

In order to achieve my research aims I adopted an IPA design as my research methodology, which was discussed in Chapter 3. Using an IPA approach helped to guide my research and facilitate participants' ability to share their stories from practice, demonstrating how they elicited patients' concerns, provided patient-centred care, and in doing so, gave insight into what it means to provide care for PLHIV

Initially, when I began my research, I had hoped that my findings would help to add to the evidence base for a communication skills course that I had developed for HIV nurses. After undertaking my research I realized that how nurses elicit patients' concerns is far broader in nature than just a set of skills that can be taught.

Developing these thoughts, and the initial driving force behind my research, led me to the conclusion that whilst we spend a considerable amount of time teaching communications skills (that can be effective in improving the nurses' ability to talk to people and gather information) we devote very little time to enabling nurses to learn how to be, and to relate to their patients. Succinctly, we do not go beyond the functional aspects of talking or information exchange in terms of practitioner-patient interaction. How the nurse is, as a person, and what influences how the nurse relates to others is of equal, if not greater, importance and significance than a set of skills. However, this is given very little thought when developing the future workforce.

My research gave me a valuable insight into what patient-centred care means and how nurses facilitated care for people living with HIV. These insights have been explored in Chapter 5, revealing how the participants elicited patients' concerns. As a result of my research findings my thinking changed. With this new insight I began to

explore the stories the participants shared, in particular how their way of being helped to create the care the patient received.

This chapter will therefore discuss the key findings set out in Chapter 5. I will discuss my findings in terms of the original research question and aims. My research question was, 'How do HIV nurses elicit patients' concerns?' and through an emergent design had the following overarching aims:

- To explore HIV nurses' stories about clinical practice.
- To explore the therapeutic relationship that develops between the HIV nurse and patient.
- To analyse nurses' way of being when developing therapeutic relationships.
- To explore through the use of stories, situations in which nurses have dealt with the emotions of patients with complex needs.
- To develop a way of thinking which contributes to the existing body of knowledge in relation to therapeutic relationships in HIV care, through the elicitation of patients' concerns.

6.2: Overview of Research Findings

The previous chapter outlined the way in which HIV nurses elicited patients' concerns through their way of being, which enabled therapeutic relationships to develop, thus allowing care to be patient centred. I will now provide an overview of these findings, before going on to discuss them in terms of the three main themes that emerged. These are: A way of being: HIV nurses' experiences; the nurse patient relationship; and factors that impacted on authentic care.

All of the nurses in the study willingly gave their time to share their experiences and stories from clinical practice to offer an insight into how they elicit and respond to

patients' concerns. The stories helped to demonstrate the uniqueness of the therapeutic relationship alongside the challenges that nurses faced when providing patient-centred care. The stories helped me to gain insight into the world of the HIV nurse, enabling me to explore how they provide patient-centred care and what this meant from their perspective. Each nurse chose to share stories which were significant to them. In doing so each nurse gave insight not only into the formation of therapeutic relationships, but also how significant relationships impacted on the nurses way of being. Thus by allowing the interviews to be led by the nurses' stories, I gained insight into their way of being whilst exploring issues that were significant to them, captured in the stories they shared. By telling the patient story within the interview, insight was given into the relationships that had developed and issues that they faced with regards to the care that they were able to deliver.

Through the process of interviewing the participants, my thoughts changed as I began to realize the skills they described and found effective, were not skills that they had been taught within a classroom setting. The most effective skills they utilized were results of experience and their own historicity. Most of the skills that participants alluded to within their interview transcripts were based on intuitive practice, as opposed to the teachable skills that I was hoping to uncover. It became clear throughout my interviews that it was the nurses' interaction with the patient that enabled concerns to be raised. For nurses to utilize any skills taught on a course, they needed to create a therapeutic relationship through their way of being.

Therefore the nurses way of being influences the care that is delivered, which makes the care patient-centred or not. As such the role of the nurse in PCC needs to be considered as it influences the care that is available to the patient. There is a need to consider how interlinked the nurse, care and the delivery of PCC is. The theories that have been discussed previously (Chapter 2) do not fully address the nurse within their conceptual framework. The role of the nurse was articulated in various PCC

models, McCormack and McCance (2006) discuss prerequisites of a nurse within their model with the assumption that before the nurse can help others they need to have insight into how they function as a person. McCormack's (2001, 2003) authentic conscious model identified the values of the nurse and patient as being paramount in shaping the care that is received. Whilst the theories mention the nurses way of being, they do not take this concept a step further by stating how the nurses' way of being impacts on their ability to provide PCC. Therefore what is fundamentally missing within these theories is the nurses' way of being that influences the care that is delivered. It has been highlighted within the research findings that, in order to create care that is patient-centered, the nurse is required to be self aware of the factors that contributed to developing their way of being.

The research highlighted how the nurse's different ways of being influenced the care that they provided. The way in which the nurses were able to provide empathic care differed depending on their own way of being, which was foregrounded by recollections of previous experiences in their lives. This is related to the work of McMurray (1995:45) who argued that we have a choice in the way that we relate to others, stating we can do this in 'an impersonal way, a functional way, or a personal way'. McMurray (1995:46) contends that this might be viewed as a choice that we make writing; 'it is only through the personal way that we fully connect with others'. Therefore when we engage personally with others this enables us to grow. According to McMurray, 'friendship' is the deepest form of personal relationship, and it is through friendship that we show love, kindness, compassion and care. Or, in other words, become person-centred. Thinking back to my reflections when caring for Joe, McMurray's thoughts resonate with me. The 'friendship' that had developed between me and Joe enabled me to be person-centred.

This is further reflected in Orla's accounts of giving her friend her vest because they didn't have their own. By sharing this experience it gave insight into her caring nature and that this caring nature developed in childhood and now influences the care that she is providing for patients. This can be linked back to Heidegger's work on historicity, whereby our past influences might influence our future or current way of being.

The link to Heidegger's thinking is also highlighted in Shauna's stories from practice where she explains how she felt her own previous experiences of dealing with challenging times had influenced the way in which she provided care. To me this highlights the importance of the nurses' previous experiences as factors that helped to develop their way of being, which then influenced the development of the nurse-patient relationship. Shauna was able to internalize her own experiences, make sense of them and then use them in a way to deepen her empathic response with patients. The nurse's historicity and experiences can be seen as influencing the nurse-patient relationship, and thus forming the basis of the care that is provided. Louis and Niamh had worked in HIV care since the start of the epidemic and shared the significance that the history of the HIV disease had on the development of their practice. They explained how the history of the disease had shaped the way in which they provided care, making them more empathetic and aware of the stigma associated with HIV.

With regards to personal experiences and the link to historicity, Iona offered insight into how she felt that arguing with her siblings had influenced and helped her to develop her way of being with patients. Harry's own historicity and identification as a gay man was acknowledged as the reason why the nursing of a dying patient had been so memorable for him.

There were a number of external factors highlighted within the research that influenced HIV nurses' ability to provide patient-centred care. These were highlighted as being the challenges of maintaining the therapeutic relationship whilst protecting the wider population from HIV. The impact of protecting the wider population from HIV is reflected in the patient stories shared by Shauna and Zayne. They describe how they dealt with very sensitive patient concerns whilst being mindful of the potential of a third party to become infected with HIV. They explain how they felt a wider responsibility to ensure that this did not happen, whilst trying to balance this with the needs of the patient. The need to protect the wider population shifts the focus of the care from the patient to others. Thus there is an added dimension (and hindering factor) to being able to provide individual patient-centred care for PLHIV. Thinking more broadly it could be suggested that the nurse is maintaining the balance of the duty of care between the individual patient and the wider community/public. In doing so they may be trying to protect the patient from future guilt that may occur as a result of infecting someone with HIV.

6.3: Discussion of Findings

I will now go on to discuss the findings in relation to the three major themes that emerged which help to identify how nurses elicit patients' concerns within clinical practice, helping to form the basis for patient-centred care to be delivered.

In order to discuss the significance of these findings and help shape my thinking I returned again to the literature that I had reviewed at the start of the study (Chapter 2). I also re-read the work of Heidegger (1926/62), as I felt this would help articulate the concepts that emerged in the next section. I will discuss my findings in relation to HIV nursing and what this adds to the current body of knowledge within HIV nursing.

The discussion will be structured in terms of HIV nursing—way of being, therapeutic relationships and the influence on patient-centred care. Before moving on to discuss what my research adds to the current body of HIV nursing and what this adds to clinical practice.

6.3.1: HIV Nursing – Way of Being

6.3.1.1: Introduction

In order to guide my thinking around HIV nursing as a way of being, I turned to Heidegger's philosophy. The concept of 'being' is central to Heidegger's philosophy, represented in the form of *Dasein*. I thought it was worth going back to the literature to explore the term *Dasein* further. Heidegger used the term *Dasein* as a starting point to explore the concept of being. Heidegger (1926:67) used *Dasein* to represent a 'possibility of many ways of being'; involving the capacity to choose from amongst several possible ways of being. With the care that I provided for Joe, I could choose to be a nurse, a researcher, a friend, a companion or a George Michael fan.

Ultimately all these components are part of my way of being, which enabled me to 'be' or 'relate' to Joe. The idea of many ways of 'being' was represented within the findings. The concept of 'being' frequently emerged within the therapeutic relationship and became central to understanding how nurses elicit patients' concerns. Heidegger suggests that *Dasein* "always understands itself in terms of existence – in terms of a possibility of itself, to be itself or not" (Heidegger 1926/62:33).

McCormack and McCance (2017:17) suggest that amongst all perspectives of PCC there is 'the recognition of the importance of 'being', with person-centeredness requiring attention to be paid to our being as a person'. McCormack (2004) stated that there are four 'being' modes at the heart of person centeredness, which acknowledges the importance of relationships. This implies that in social context, the

person cannot be separated from their social world, the concept of 'place' impacts on nursing practice and being recognised as a person is a fundamental human need.

Throughout my research it was discovered that the nurses' way of 'being' enabled PCC to be delivered. The following themes will be presented and discussed: being as care, being as authentic, being as aware and being as freeing. Supportive extracts from the data and relevant literature will illuminate these concepts, in keeping with the IPA tradition.

6.3.1.2: Being As Care

Within all the interviews there was a strong sense that the way in which the HIV nurses provided care for patients was linked to a patient's outcome. Being as care emerged as a theme within this as it gave insight and helped shape my thinking with regards to how care was provided and how nurses facilitated the care being given.

Harry's philosophy on care is represented as being a partnership approach where the nurses are friendly with patients whilst providing care, with the overall aim being to give the patients the skills they need in order to be able to solve their own problems. Harry expands on this way of being to provide care further by saying the greatest thing you can do for a patient is to establish their concerns and help empower them to do something themselves about their problems, Harry's way of being also provides an example of the application of Heidegger's thoughts on caring, in relation to providing care in a leaping in or leaping ahead way, as mentioned Chapter 2, Harry described a 'leaping ahead' approach to care supporting and empowering his patients in order for them to make choices about their health and to find the solutions to their own problems. This is opposed to a 'leaping in' style of care that fixes the patient's concerns. Harry's approach to patient-centred care appears central to his way of being. The type of care suggested by Harry also helps to

support my pre-understandings in Chapter 4, which suggested that patient-centred care facilitates empowerment. This way of being supports Rodger's (1984) principle theories, which suggest that each individual has considerable qualities which they are able to draw on to gather strength and in doing so can find a way to work through difficult times. This way of being as a nurse enables care to be delivered to patients, which is both patient-centred and empowering.

Orla describes the process of building up a relationship with a patient who did not want to be cared for. Orla goes on to describe the difficult process that affected her 'being as care' and how she developed a relationship with a patient who was struggling with his new diagnosis. Reading Orla's extract reminded me of the work of Mayeroff (1997:46), who explored reciprocity, the idea of a mutual partnership, and acknowledging that people may not be able to reciprocate care, especially if they are unable to care for themselves. Within Orla's extract it would appear that the patient was trying to make sense of his diagnosis and was unable to reciprocate the care Orla was demonstrating, which is illustrated within the patient story. The patient was struggling to meet his own needs with regards to his diagnosis, and was therefore unable to engage in a reciprocal relationship with Orla. For Orla this was initially very significant and she struggled with her way of being and how she was providing care to the patient. Instead of disengaging from the patient, Orla's self-awareness enabled her to acknowledge what was happening for the patient and in doing so utilized her way of being to provide care to the patient.

Allannah suggests that the process of providing care goes beyond the person who is providing care, suggesting that environment influences the care being provided; advocating for the need to create a caring atmosphere. Allannah suggests the clinic becomes a place where the patient can be open and not feel judged. This perspective is supported by Morgan (2012) who suggested that the practice of

patient-centred care is dependent on the care environment. This implies that in order to deliver patient-centred care, care extends beyond the person to where the care is being delivered. However, the impact of place on patients' experience is still under-researched (McCormack and McCance 2017).

Allannah's observations support my pre-understandings in that I think nurses provide sanctuary for HIV patients. Allannah's suggestion also helps to support further thinking, which will be expanded on within the implications for practice with regards to creating an HIV nursing philosophy. This is an ethos which goes beyond the individual nurse, as illustrated in Allannah's story. For Allannah, her 'being' as care is interwoven with the environment, she is in. This then enables Allannah to provide care to patients.

6.3.1.3: Being as Authentic

Within my reflexive accounts of caring for Joe, 'authentic being' was present; particularly the incident where we were outside remembering songs from our early teenage years. This way of being was authentic and facilitated Joe's ability to be himself, in a safe place. It also enabled me to reach a different level of understanding of Joe's care needs. Through this way of being Joe was able to share some of his deepest concerns, around dying and the thought of not being with his mum. Had my way of being been different then perhaps these concerns would have remained unheard.

I have thought a lot about my way of being and wondered if I always act in an authentic way or had there been times when I had been inauthentic. If so what were the benefits of this style? Aranda and Street (1999) suggest that there is a functional aspect to nurses not being authentic and refer to this within their work as being when the nurse acts as a 'chameleon' in order to provide care to the patient. In doing so,

the nurse becomes the nurse the patient needs. This also relates to Heidegger's work which suggested that *Dasein* can choose to be authentic or inauthentic, and that being inauthentic allows a person to fit in and conform with others. Jack and Wibberley (2014) highlighted the influences of nursing culture in determining how emotions could be developed within student nurses. Their research suggests that there is a culture within nursing that does not allow for, and makes it difficult for, nurses to be able to demonstrate their own emotions when caring for patients. Jack and Wibberley (2014) go on to suggest that nurses need to attempt to develop a balance between an appropriate level of intimacy and a level of detachment. This is perhaps why I struggled at times with my relationship with Joe, as I constantly re-addressed the balance between intimacy and detachment.

This idea of fitting in with others is highlighted in Heidegger's work as 'the they'. Heidegger (1926/1962;32) believed that the 'they' (i.e other people) prevent us from being ourselves and in doing so, restrict our many possibilities of being. According to Heidegger the 'they' take away our choices, which results in us falling into inauthenticity, from which we must then return. For me this is linked to the wider culture of nursing and the need to 'fit in' with colleagues and the need for emotional 'balance' within clinical practice (Jack and Wibberley 2014).

When I reflect on my experiences of HIV nursing I believe we have formed our own culture, and that we (HIV nurses) have been providing care in a bubble, isolated from the wider context of nursing. Within hospitals HIV nurses provide care in sexual health clinics, which are often at the back of the hospital. Alternatively, we work in infectious diseases units, which are often on isolation wards. This physically removes us or distances us from the wider culture of nursing. Due to identifying with the stigma associated with the HIV condition, HIV nurses in my experience remove themselves from nurses in other disciplines, who are often viewed as the

perpetrators of stigmatizing care (Hodgson 2006). Therefore I believe that HIV nursing is carried out within a discrete sub-culture, within the overarching culture of mainstream nursing. Although these opinions are not represented within the scholarly literature, this has been my experience of working for years within the 'disease area'. Relating back to identifying with the 'they', PCC not being viewed as essential to patient outcomes poses a challenge within the subculture of HIV nursing.

Initially, I viewed my practice with Joe as being 'authentic'. After returning to the literature and the work of Heidegger my thoughts changed. I now view my way of being as both authentic and inauthentic and adapting according to his needs to allow me to be the nurse that he needed. When I consider the benefits of this approach to patient-centred care, I wonder if my initial thoughts around care being authentic or inauthentic were too simplistic. I wonder whether authenticity should be viewed more fluidly with the concept of authenticity being more flexible, and that there are boundaries of authenticity that a person can work within that ultimately make up their authentic self. For example, when working with Joe there were times when I was inauthentic, particularly when I said I supported his choices, when clearly this went against my own personal beliefs. By being inauthentic it enabled Joe to receive the care he needed. On reflection, being inauthentic enabled me to elicit his concerns that he needed to share and give him the support he needed.

Harry's being as authentic is expressed when he acknowledges the privileged position he feels when providing care for PLHIV. Harry describes an authentic way of being that people naturally feel comfortable around him and are therefore able to disclose their concerns. Harry also suggests that this is something that HIV nurses should be more proud of, as this is a natural way of being, I wonder how many HIV nurses acknowledge this 'skill' or have this authentic way of being, as this is not mentioned within all the participants interviews. The work of Dart (2011:16) helps to

articulate Harry's way of being within therapeutic relationships, stating that this should be "one in which the patient feels comfortable being open and honest with the nurse".

Within Dart's (2011) definition it is not clear whether being authentic is necessary in order for a therapeutic relationship to develop. Thinking about Arands and Street's (1999) work, it would appear that nurses change in order to meet the needs of the patient. I would suggest that a relationship where a patient feels comfortable being open and honest with a nurse does not require the nurse to necessarily act in an authentic way. It requires the nurse to be responsive to the patients' needs. Thinking back to Harry's interview, he did have a very gentle warm personality that made him easy to talk to. Therefore the way in which he 'was' would create the care that is delivered, making the care responsive to patients' needs.

Shauna also describes an authentic way of being when referring to a patient who had remembered the care that Shauna had given. This suggests that it was more about the way in which she came across to the patient than anything that she said. Shauna acknowledges that her way of being extended beyond words and was more subjective in the form of a presence that the patient felt comfortable with and subsequently remembered. This is in line with Dart's (2011) arguments concerning the nature of the therapeutic relationship, as well as Baykin and Schoenhofer's (2001) work, who suggested that the notion of authentic presence enables the nurse to demonstrate care.

6.3.1.4: Being as Aware

Whilst interpreting the data there was a sense that in order to provide care for PLHIV the nurses needed to demonstrate an awareness of the patients' 'issues' alongside their own personal beliefs and values. As such, they need to acknowledge their

values and beliefs around homosexuality, condomless sex, prostitution and IV drug use in order for them not to influence the care that is delivered. This awareness seems to be significant in the development of the therapeutic relationship. As this was a fundamental aspect in the development of the therapeutic relationship it has been represented as being as aware.

This concept was reflected in over half of the participants' interviews, which highlighted the reflective nature of the interviews and openness of the participants. I have chosen to demonstrate how this is represented within the findings using Erin and Iona's narrative accounts, as I feel that this best represents the theme of being as aware in the findings.

Erin demonstrates this awareness by acknowledging that she is not a 'touchy feely person' but validates her own way of being as useful, stating that different people bring different things to the table. Being as aware, as described by Erin, enables her to provide care in a way that is in line with being as authentic. As a result of this awareness she is able to focus on her own style with patients and states that she uses humour in order to relate to patients. By having this awareness Erin is able to validate her style of patient care and this enables her to be authentic, as well, as being aware within the nurse-patient relationship. Thompson (2005) suggests that the path to authenticity is difficult but more rewarding, requiring a person to learn to deal with the anxiety of revealing their true selves. Reading Thompson's work and Erin's reflection made me consider how difficult being authentic and providing patient-centred care could be for a nurse. I will therefore consider this further within the implications for practice section.

Iona also affirms Erin's being as aware by highlighting that other nurses could get information from patients more effectively than she could, and in doing so she

wonders if they use different skills. This level of awareness highlights Iona's reflexive nature acknowledging the unique aspect of providing care and the individuality of the nurse patient relationship. Iona demonstrated being as aware through evaluating and comparing her skills to others.

Making sense of Erin's and Iona's way of being highlighted for me the need for reflexive practice and for nurses to be self-aware, which came through as a strong theme worthy of further thought. I will therefore discuss the need for reflexive practice and self-awareness in HIV nursing further with the implications for practice section as a separate, yet related theme.

6.3.1.5: Being as Freeing

Being as freeing is reflected in the transcripts as being the HIV nurses' ability to allow the patient to be free to choose their own treatment experience and still remain engaged in care. In relation to my experiences with Joe, my way of being supported him to make choices about treatment that went against the traditional bio-medical model. My way of being facilitated the nurse-patient relationship and enabled Joe to receive care in the way he wanted to receive care. This provided Joe with care that was lead by his needs and responded to his needs, whether that was to support him to take treatment or to not take treatment.

Allannah also alludes to being as freeing when she explains that people have their own personalities and ways prior to having the diagnosis of HIV. Allannah's extract highlights the idea of allowing people to be free to be who they are. Within Allannah's interview she goes on to suggest that she believes her role as a nurse is to accept this and help patients to live a full life.

Identifying these multiple ways of being within the findings enabled me to think about what being a HIV nurse meant. I began to consider not only what being a HIV nurse meant, but questioned how to be a HIV nurse in line with Heidegger's concepts "*Dasein* as an entity that can decide whether or not to be" (Inwood 1997:23). How does this newly acquired knowledge shape my own way of being as a HIV nurse? How do I chose to 'be' a HIV nurse based on my research findings?

After highlighting and discussing the HIV nurses' different ways of being, I wanted to explore how the nurses' way of being impacted on patient-centred care.

6.3.2: Therapeutic Relationship's and the Influence on Patient-Centred Care

It became clear from the transcripts that the nurse's way of being directly influenced the development of the therapeutic relationship which then enabled the delivery of patient-centred care. The ways of being that have been highlighted above were presented within the therapeutic relationship and facilitated the care that was given.

The therapeutic relationship was a central theme throughout the findings and was pivotal in understanding how nurses elicited and responded to patients' concerns. An interesting theme emerged throughout Harry's, Shauna's, Iona's and Orla's interviews with regards to the influence that previous experience had on shaping the therapeutic relationship.

This is related to the Heideggerian concept of historicity (as previously discussed in Chapter 2), which supports the idea that each nurse brings with them a unique set of experiences, alongside their past way of being, into their nursing practice. This can be supported by reference to the work of Meutzel (1985:35) who suggested that "the

ability of the nurse to partake in a therapeutic relationship is dependent on the nurse having developed, both personally and professionally”.

The significance of these experiences, and the impact that this has on the nurses' way of being, made me consider the importance of self-awareness within HIV nursing. The need to be self-aware within HIV nursing, alongside the need to be aware of the factors that influence the care that is being provided, appeared to be paramount in how patients' concerns were elicited.

Within this thesis I have been explicit about the impact that caring for Joe has had on shaping my way of being. My history of providing care for Joe has influenced the way I provide care and how I will provide care in the future. This is line with Heidegger's thinking regarding “*Dasein* already being in the world, already dealing with what was in the past, whilst projecting into the future at the same time being preoccupied with the works of the present” (Collins and Selina, 1988:33).

Joe had been a significant patient for me, Joe had challenged my beliefs about nursing, making me question how I provided care which helped to shape the nurse I am. The experiences that I had caring for Joe influenced the care that I gave, not only to Joe, but to other patients. These experiences have shaped my nursing practice influencing the care that patients receive and have altered my thoughts with regards to how, as a nurse, patients receive care from me. The care that I now give to patients and the way in which their stories help to shape my way of being, will influence the care that I give in the future. Certain aspects of patients' stories, such as their choices not to take treatment, cause me to reflect back to my previous way of being in order for me to provide care for them in the present. These experiences collectively influence my way of being and the care that I provide.

This conclusion led me to an understanding that *Dasein* has its being in all three temporalities, all three influencing the care that I now give. Thinking about the participants' accounts also made me think about the significance of the stories that they chose to share, the impact that these have on the therapeutic relationship and the delivery of patient-centred care.

In chapter 2, I explored the meaning of historicity and HIV nursing. I suggested that HIV nurses provide care that is influenced by the history of the disease area, providing care that has changed from delivering palliative care to that of supporting people with a long-term condition. I have further highlighted this through engaging with stories of how care had been delivered when there were limited treatment options, later in this chapter.

6.3.3: Why is Providing Care for People Living with HIV Different?

I wanted to explore my research findings in order to understand if HIV nursing is different from other disease areas. The ways of being that had been described and the themes that emerged could potentially be transferred to nursing in general. I wanted to explore what made providing care for PLHIV so different. I had been a HIV nurse for over 20 years and believed that nursing PLHIV is different and was keen to explore whether this would be evident in the data.

Within the participants' transcripts there was a strong sense that the nurses, through their approach to patient-care were mindful of the effect stigma had on their patients' physical and mental well-being. This is supported by Sowell and Phillips (2010:311) who suggest that "nurses have the most frequent interactions with HIV clients; and can provide crucial assistance to patients to develop positive coping strategies to deal with the psychological challenges of the illness and the stigma associated with this particular disease". This is reflected in Erin's case, as her rapport with the family

facilitated a buffer to the self-stigma the patient was experiencing. Allannah highlights the unique nature of the HIV virus, stating that it is like no other illness and as a result people are too afraid to tell anybody about it, forcing patients to cope with the illness alone.

The impact of stigma is clearly seen in Erin's case, highlighted by a patient becoming aware of her diagnosis in a very public way as a result of the person who infected her being prosecuted. You can almost see the tabloid headlines 'Death sentence for victims of HIV positive sex crazed man'. Stigma and self-stigma affects people's ability to obtain access to the treatment they require and access the support that they need. Self-stigma forces patients to hide their diagnosis and live in secrecy. Stigma and self-stigma were a constant theme within the therapeutic relationship that developed between Joe and myself.

Throughout the participant's interviews stigma appeared to be in the background, heavily influencing the participant's ability to elicit patients' concerns. The non-judgmental nature of the HIV nurse enabled patients to disclose their concerns in an environment without fear of rejection. This process enabled the nurse to then deliver the care that the patient needed and enabled the therapeutic relationship to develop.

Although patient stigma appears to be a central component of the issues explored in the participants' interviews, it was not expanded on with any great depth by the participants other than being alluded to in the background. Reflecting on this I wondered if this may have been a result of the questions that I had asked within the interview or whether the participants assumed that as a HIV nurse, I would be familiar with the issues surrounding stigma and have felt that it wasn't important to discuss.

Within the literature it has been suggested that nurses often fear the contagious aspect of the HIV disease that impacts on their ability to develop therapeutic relationships (Valimaki et al 1998, Lohrmann et al 2000, Witt Sherman and Quellette 1999, Neuman and Makhauf Obermeyer 2013, Florom–Smith and Santis 2012). The contagious aspect of the disease was identified as being one of the significant differences that makes HIV nursing different from other nursing. The fear of the contagious aspect of the disease was not observed within this research, despite participants being very aware of the risk of onwards transmission of the infection, as detailed by Zayn and Shauna’s experiences of the public health/protection aspect of their role. None of the participants suggested that they were concerned about contracting HIV from their patients.

Whilst listening to the participants stories it became clear that they were passionate about the care they provided for PLHIV. There was no element of judgment with regards to how patients had contracted the virus as previously mentioned within literature, and the issue of fear of transmission was never raised. Therefore these findings can be used to support the positive therapeutic relationships that have developed when caring for PLHIV.

I believe that providing care for PLHIV is different due to the issue of stigma. The ways of being that have been described by the nurses within my research could be translated into any other disease area. Therefore the thing that makes HIV nursing different is the concept of stigma and the nature of stigma, including its historicity. The nurses working within this area of care must be aware of the issues concerning stigma that PLHIV face, and the potential effect that this can have on the nurses’ ability to provide care. The nurses need to be mindful of the effects that stigma has on the patient and how this then impacts on PCC.

6.4: What Does this research add to the Current Body of Knowledge on HIV Nursing?

What makes this research original and therefore add to the body of knowledge is that it explores an area of HIV nursing that has not previously been explored within the literature. The research is of importance as it demonstrates how HIV nurses elicit patients' concerns and what compassionate patient centred care (PCC) means in the context of HIV care. It explores the use of story telling to demonstrate how nurses elicit patients' concerns in order to provide empathetic care. It also acknowledges the moral and ethical dilemmas that HIV nurses may experience when trying to balance the needs of the patient in order to provide PCC with the need to protect the wider public from potentially acquiring HIV.

The stories that have been represented and discussed within this thesis offer an insight into the therapeutic relationships that are developed between the nurse and PLHIV. The research also gives insight into what it means to 'be' a HIV nurse. To date, research has focused on the negative and stigmatized relationships that occur in healthcare professionals looking after this cohort of patients (Valimaki et al 1998, Lohrmann et al 2000; Witt Sherman and Quелlette 1999; Neuman and Makhouf Obermeyer 2013; Florom-Smith and Santis 2012). My research is different as it explores the positive aspects of caring for PLHIV and the relationship that emerged between the patient and the nurse. This facilitates PCC and therefore adds valuable thinking to the current body of knowledge with regards to nursing, as it explores the positive relationships that take place within the healthcare setting.

The research articulates how complex patient care can create a deeper sense of compassion for nurses, that they are able to translate to other patient's care, in order

to provide PCC. It also explores the significance of patient stories in the development of the nurses ability to create positive therapeutic relationships.

It was clear that the nurses genuinely cared for the patient group and wanted to provide care for PLHIV. This is in contrast with other studies which view PLHIV as being responsible for their disease and not welcome within care settings (Hodgson 2006, 2010; Valimaki et al 2008; Vance 2008; Neuman and Makhouf Obermeyer 2013; Florum–Smith and Santis 2012).

The way nurses 'were' with these patients was further explored through Heidegger's concept of *Dasein* which articulates the way in which we 'are' in the world. *Dasein* takes into consideration that the world and person, rather than being two separate entities, are inextricably linked. *Dasein* also acknowledges that we are a product of our past ways of being. Identifying these ways of being and the link they have to Heidegger's thinking enables discussions to emerge around the multi-faceted nature of 'being' a HIV nurse, so the HIV nurses 'multiple ways of being' adds to the current body of knowledge on PCC.

I believe that understanding HIV nurses' way of being and how relationships are formed with this cohort of patients, offers insights into how PCC is provided within this area of practice. The findings, and discussions around the findings, can be used to influence how future HIV nurses may develop their practice and establish therapeutic relationships that promote patient-centred care. Developing a way of being in HIV nursing to provide care that is patient-centred cannot be easily taught in a classroom setting. However, there are a number of strategies that can be used to help nurses develop their way of being, I will now go on consider the implications of my findings for clinical practice.

The research also adds a piece of the jigsaw to theoretical discussions with regards to what is meant by the term PCC in the context of HIV care.

6.5: What are the Implications for Practice?

I became keen to explore how my findings could be used within clinical practice and what value my research findings added to HIV nursing care. Whilst it may not be possible to draw general conclusions from the study of ten nurses, I feel that there are a number of implications for practice that have emerged from the findings.

Through the use of patient stories, the way in which nurses elicit concerns can be viewed as being more than just their ability to communicate with patients. In order for nurses to be able to provide patient-centred care they first need to find a way that enables them to 'be' with the patient. The nurse's ability to 'be' with the patient then creates a therapeutic relationship, so care may be provided. Within the participants' narratives stigma and the need to consider the wider public health were viewed as being implicit factors, which inhibited the nurses' ability to always provide person-centred care.

Based on the implications of my findings, I believe that the following three areas would benefit from further exploration:

- Self-awareness.
- Reflection within clinical practice.
- Developing a HIV person-centred nursing framework.

6.5.1: Self-awareness

As previously mentioned in Chapter 2, since the beginning of the HIV epidemic PLHIV have experienced stigma and discrimination and have often been blamed for their illness. This might be due to HIV being identified within subgroups of society, such as gay men, prostitutes, and ethnic and racial minorities. As a result, the nurses

that care for PLHIV have often had to challenge some of their pre-held views (concerning, sexuality morality and often death) in order to provide care for PLHIV. Thus in order for nurses to be able to provide care for PLHIV they need to be self-aware, with regards to their thoughts and feelings in relation to these sensitive and challenging issues.

After undertaking my research I now consider how important self-awareness is with regards to eliciting patients' concerns and providing PCC. My research highlighted how fundamental self-awareness is, within nursing, in order to develop therapeutic relationships. This work is reinforced by the work of Severinsson (2001) who suggested that nurses need a degree of awareness in order to enable a caring philosophy to be created, which then facilitates care being provided.

Within the findings it became evident that the nurses were self aware with regards to the care that they provided. It was clear that the nurses genuinely cared for PLHIV and care was given in a very non-judgmental way. The theme of self-awareness emerged through the stories that all the participants shared concerning challenging patients. Within the research the complex patient stories that were shared within the interviews were both powerful and cathartic for the participants. There was a strong sense that by telling the patient's stories the participants were making sense of the patient's story and their role when providing care. Had I realized the significance of self-awareness within HIV nursing earlier, I would have expanded on this further within the interviews to explore how nurses developed their self-awareness. This is something I hope to pursue in future research.

Fletcher and Baldry (2000:312) state that "self-awareness is found in a minority of individuals, who could be described as being 'naturally' self-aware. This could mean that the majority of people would need to develop self-awareness". In my findings,

self-awareness seemed to be more of a 'way of being' as opposed to a separate process. Fletcher and Baldry (2000) go on to suggest that self-awareness could be developed in clinical practice by using reflexivity, keeping journals, observing what other people are doing and by receiving feedback. This made me consider how this might help create self-awareness and help support the nurses' way of being.

Based on my findings I believe that in order to provide care for PLHIV the nurse needs to be self-aware. By having self-awareness this will then create insight into how their way of being is developed, (as discussed in Chapter 5), which will then influence the therapeutic relationship and, ultimately, the care that is delivered. As a result of my findings and acknowledging that people are not naturally self-aware, patient outcome strategies should be included within clinical practice to enable the nurse to become self-aware. However, I acknowledge that this is very difficult and challenging within healthcare settings (see 6.5.2). Despite the perceived challenges of encouraging self-awareness, Rungapadiachy (1999) suggested that becoming self-aware is mandatory within the caring profession, and that it consists of three aspects: thinking, feeling and acting (Jack and Smtih 2007).

Exploring the literature on self awareness it became apparent that becoming self-aware is considered to be a conscious process, in which we reflect on 'understanding ourselves' (Nicol and Dosser 2016, Eckroth–Bucher 2010, Rawlinson 1990). Within this process we begin to know our own strengths and our own limitations; and so begin to understand our own emotions, and also the impact that our behaviour has in therapeutic relationships with others (Jack and Miller 2008). The process of becoming self-aware is an ongoing process that is never complete and requires us to constantly re-evaluate where we are, what we have learnt and what we still have to learn (Del Rio and White 2012, Attard and Baldacchino 2014, Burnard 1988).

My data highlights how significant self-awareness is, within clinical practice, to improve patient outcomes. I will, therefore, explore ways in which HIV nurses can develop their way of being to influence the care that patients receive.

6.5.2: Reflection within Clinical Practice

It has been identified throughout this thesis, (the literature presented and the stories shared by the participants), that PLHIV have complex psychosocial needs that influence the therapeutic relationship. Due to these complexities it is important that nurses find a way to reflect on these issues and the complex nature of the care that they provide.

Throughout the interview there was evidence of reflexive practice within the interviews as participants recalled and discussed issues from their practice. This took place through informal story telling, as opposed to any formal exercise. This is reflected by Coward (2011:883), who suggests that ‘the majority of nursing literature referring to the process of reflection and reflective practice concentrates on the underpinning concept of learning from what we do in practice’. Coward (2011:883) goes on to suggest ‘the terms ‘reflection’ and ‘reflective practice’ have become problems” in nursing “due to the sheer weight placed on them for students with regards to assessment strategies”.

Thompson and Pascal (2012) suggest that the underpinning theory of reflective practice is rarely integrated within clinical practice. There is considerable confusion amongst many practitioners as to what reflective practice involves.

Thinking back to my own experiences of reflective practice, I have been guilty of viewing this process as a formal exercise to meet the requirements of a course, as opposed to encouraging deeper thinking and deeper learning for my practice.

Typically, I would use the Gibbs (1988) reflective cycle to enable me to consider my feelings about a certain situation. In order for this to take place I would have to acknowledge that a situation had triggered some form of uncomfortable feeling, or conversely, a feeling that something had gone well. Reflexive practice is often viewed as an effective method of learning within clinical practice (Boud et al 1985, Jarvis 1987, Murphy and Atkins 1994, Schon 1987). I was keen to explore alternative ways to facilitate reflection within clinical practice.

I returned to the work of Heidegger in an attempt to seek an alternative perspective to help aid my thinking. Heidegger (1966:53) talks about 'meditative thinking' which I believe is important to consider in terms of how we effectively implement strategies to reflect within clinical practice. Heidegger talks about 'meditative thinking' in the following way:

"Meditative thinking demands of us not to cling one-sidedly to a single idea, nor to run down a one-track course of ideas. Meditative thinking demands of us that we engage ourselves with what at first sight does not go together at all".

Using a meditative thinking approach as suggested by Heidegger would enable me to go beyond any obvious first reflective accounts and develop a deeper understanding of a particular situation. I was keen to explore how I could use 'meditative thinking' to improve my clinical practice.

During a National HIV nurses' conference, I listened to a moving patient story about the care that he had received when an inpatient in a local hospital. He talked about how the experience had a negative and stigmatizing experience on him. I began to explore how we could encourage nurses to learn about practice based experiences

from a HIV specialist nurse. I wanted to think of ways to explore how we could learn from this patient's experience and in doing so improve standards of care for PLHIV.

My colleague informed me of a pilot study he had been involved in at Kings College Hospital called Schwartz center rounds. Schwartz center rounds were being used in his practice area as a way of providing a forum for staff to explore the challenging psychological and emotional aspects of caring for patients. Schwartz center rounds first originated in America and involve a process that enables hospital staff to come together to explore the challenging psychosocial and emotional aspects of caring for patients (Firth-Cozen and Cornwall, 2009).

The rounds aim to improve communication and relationships between patients and HCPs. The rounds address issues that are rarely discussed in education settings such as, "the management of team conflict, stories of hope and miracles, instances when providers become patients, the impaired professional, the impact of patient violence, instances when cultural or religious beliefs impair providers ability to communicate, the impact on providers making a mistake" (Lown and Manning 2010:1074).

The rounds usually last for an hour and are case-based, interactive discussions which take place based on the team's preferences. They are usually led by a physician or professional facilitator. The session begins with a brief presentation of a patient or family's case, facilitated by a member of the care team involved in the care delivery. This brief presentation takes into consideration multiple perspectives on the psychosocial topics and highlights the importance of patient confidentiality. The presentation gives consideration to multiple perspectives, including psychosocial issues and emphasizes the importance of confidentiality. The audience is encouraged

to participate in the discussion section, which is again facilitated, by the physician or professional facilitator (Goodrich 2001).

The purpose is to enable staff to discuss the emotional nature of the care, in contrast to critical incident analysis, which focuses on how incidents happen and what can be learnt. The rounds are not the same as clinical supervision, as their focus is not to explore alternative approaches to care whilst offering support. The Schwartz center rounds are designed to explore the emotions of healthcare professionals triggered through providing care for patients.

Joe had been a significant patient for a number of professionals, so it appeared appropriate to use this approach in order to make sense of some of the emotions that had arisen as a result of caring for him. Thinking about my own practice, I wonder how acceptable the idea of having a Schwartz center round would be in order to explore the emotional issues that surrounded Joe's care. Subsequently, we decided to use Joe's care as a pilot for potentially implementing Schwartz centre rounds into clinical practice.

In America the rounds take place in diverse environments, including universities, medical centres, community hospitals, nursing homes and out patients settings (Goodrich 2001). The rounds are set up to be a safe space for all involved and confidentiality is paramount. Patients' names are changed and participants are asked not to share any information outside the rounds (Goodrich 2011).

An independent evaluation of the rounds in the United States (Lown and Manning 2010) identified multiple benefits for the individuals and teams who took part in the rounds. These benefits also had a positive influence on the care team. Participants felt that the rounds supported them to provide compassionate care for patients,

which helped to reduce their feelings of isolation and stress. Participants also reported feeling better supported when caring for patients and felt that as a result of the rounds they had a better understanding of their colleagues' roles.

Previously there had been a sense of frustration around Joe's inability to take treatment that the healthcare professionals involved could not understand. At times this sense of frustration was directed at me and the psychologist involved in Joe's care. Throughout the Schwartz center round the emotional impact that caring for Joe had created for the professionals involved was discussed. This approach also provided an opportunity for concerns to be validated, and emotions such as anger, empathy and frustration to be acknowledged.

Goodrich's research (2011) found that the rounds helped to increase respect, empathy and understanding between staff. Goodrich (2011:14) suggested that 'Schwartz center rounds may provide a role modeling opportunity as senior staff not only acknowledge their challenges but simultaneously model to junior members of staff the importance of discussing the emotional side effects of caring for patients'. Based on personal experience I suggest that Schwartz centre rounds could be used in clinical practice to improve patient outcomes. The rounds lend themselves to Heidegger's thoughts around 'meditative thinking' as healthcare practitioners are not locked into one sided thinking, and are encouraged to engage in thinking about a case in a different way.

Despite the success of the Schwartz center round within my own practice area, I believe that we are a long way from seeing this as a regular feature within my practice setting. With this in mind, I returned to my original thinking with regards to what the implications of my research would be on clinical practice. After much consideration I felt that my findings highlighted the need for reflective practice to be

fundamental to the process of developing the nurses' way of being/increased self-awareness. This in turn, influences the development of the therapeutic relationship. In order for practice to shift and move forward, role modelling and good leadership within HIV nursing is required to influence nurses to think about practice differently.

6.5.3: The Concept of a HIV Person Centered Nursing Framework.

Within my research I wanted to establish if any new concepts that had emerged from within the data could be used to influence clinical practice. I also wanted to see how these concepts could be linked to wider theories within nursing. According to Rodgers and Knaft (2000:20) "the development of concepts is important in order to expand nursing knowledge, as concepts are a form of nursing inquiry that expands the knowledge base of nursing and related disciplines".

Whilst making sense of my findings and their implications for practice, I began to explore different nursing models as a way of establishing if HIV nurses could use the various philosophical underpinnings that were used within these models to underpin their practice. I explored Peplau's (1952) model around interpersonal relationships and felt that this was the most appropriate for describing how the HIV nurses within my research facilitated care.

I acknowledge the relevance of Peplau's model (which describes the 6 nursing roles that lead in to different phases of the nurse patient relationship) to HIV nursing, and how this could be used to guide thinking within HIV nursing. I was keen to explore how my research moved thinking forward and how it added to the body of knowledge within HIV nursing. After much contemplation and returning to my findings, I began to see a framework of care emerging from the participants' accounts of how they provided care. Initially, I hoped to use my findings to propose a model of HIV nursing practice that could be used to inform current practice.

After further thought I reconsidered, as I felt that by suggesting a model as opposed to a framework, I ran the risk of developing a tick-box concept to HIV nursing practice. With a tick-box concept nurses could suggest that they are following the model based on limited understanding. I was also mindful that patient care is delivered by a multi disciplinary team of people, and that suggesting a philosophy of practice would encompass factors, that have been highlighted in my research and the wider literature, as being important in providing patient-centred care. I therefore believe that the implementation of a HIV person-centred nursing framework into clinical practice would have a greater impact on patient care, as opposed to suggesting a model of nursing care.

The diagram below illustrates the components of what I think are essential to being able to develop a HIV nursing philosophy of care. I have represented this framework in a visual format in order to describe the components that contribute to the HIV person-centred nursing framework.

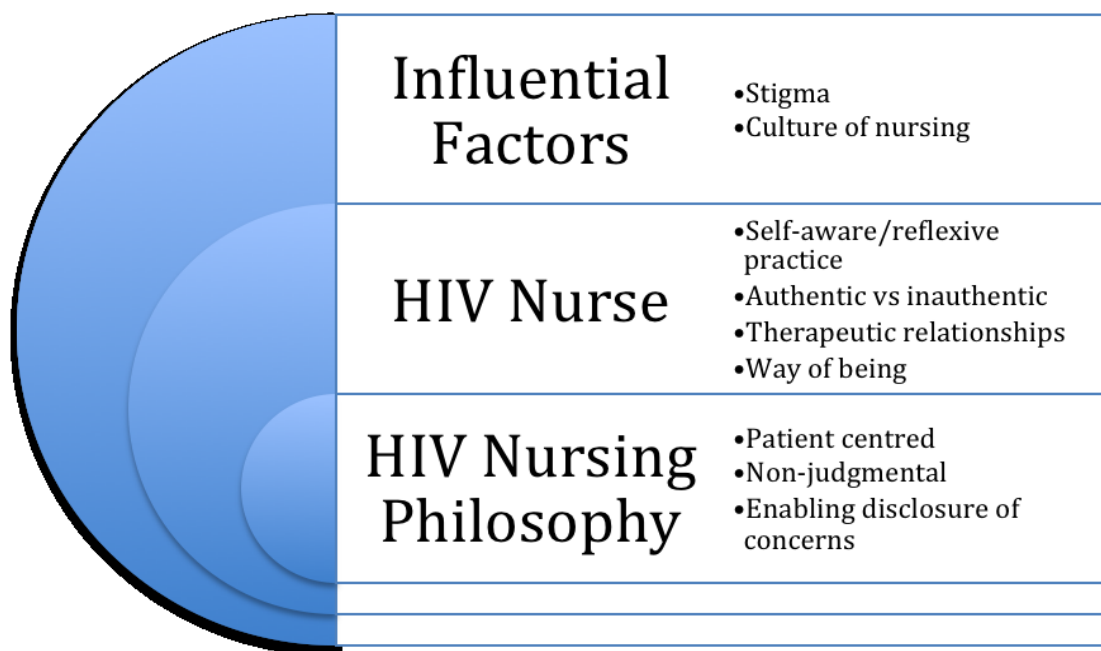


Figure 1: HIV Person Centred Nursing Framework.

The HIV nursing philosophy is central to the HIV person-centred framework. Within the HIV nursing philosophy non-judgemental care is paramount, enabling care to be patient-centred, facilitating the disclosure of concerns. In order for the HIV nursing philosophy to be created within clinical practice, we need nurses that are self aware, reflexive practitioners, who will facilitate the development of authentic/inauthentic practice. This then influences the therapeutic relationship that is being developed between the nurse and patient. Fundamentally, the therapeutic relationship, and the nurse's ability to be either authentic or inauthentic, is based on the nurses' way of being.

HIV nursing is influenced by stigma, which is based on the history of the HIV disease and societies' misperception of HIV. The influence of stigma and self-stigma is always present in the background of HIV care delivery. Another influencing factor within HIV nursing is the culture of nursing, in which nurses learn their way of being and how to relate to patients. HIV nursing and the nursing culture in general is influenced by the bio-medical model, which focuses on disease management and evidence based care. Although the bio-medical model is shifting towards a more patient-centred approach, medicine and disease management remains a dominant focus which influences nursing practice. Therefore the culture of nursing is a significant influencing factor in the establishment of the HIV nursing philosophy.

My research identified that the HIV nurses' way of being is made up of multiple ways of being, explained through Heidegger's theory of *Dasein*. The nurses' way of being is developed through a process of self-awareness and reflexive practice. The nurses'

way of being at times is both authentic and inauthentic in order to 'be' the nurse that the patient needs them to be. As a result of this process therapeutic relationships are formed. These therapeutic relationships then act as a platform for care to be provided, facilitating the disclosure of patients' concerns, which in turn leads to patient-centred care.

It was identified that there were a number of factors that had an impact on the development of these core components of HIV nursing practice. These factors were significant in developing a HIV person-centred nursing framework. These factors have been identified as stigma, the influence of the bio-medical model and the culture of nursing.

Within the research, stigma appeared to be in the background of the patients' stories that were told by the participants. It was clear that having an awareness of the stigma that patients faced was an influential factor in providing care. The therapeutic relationships that were formed within these stories from practice, acted as a buffer for the stigma, or fear of stigma, that patients experienced.

It was acknowledged that HIV nursing takes place within the influence of the bio-medical model. What was also evident was how nurses acknowledged this influence but chose to develop relationships that went against such a model, (as my reflections on Joe illustrated). This was also demonstrated through Harry and Holly, who established a way to provide patient-centred care that was informed by bio-medical knowledge but was not driven by this approach. This is important to acknowledge, as this shifts away from the bio-medical model, and focuses on the concerns of the patient, as opposed to the bio-medical management of HIV, enabling patient-centred care to be provided.

HIV nursing still sits within the wider culture of nursing which has a focus on developing and teaching skills to nurses in order to meet the patient's need. This process does not lend itself to facilitating the nurse's own style of practice and the development of the nurse's way of being. Within the research, the culture of practice described inhibited the nurses' ability to provide patient-centred care, due to care being delivered in a style that ticked boxes. Zayn illustrates this within his interview when he shared the dilemma he faced when giving a patient a positive HIV test result on Christmas Eve. I also felt I needed to defend the care that I gave Joe, hiding behind the psychological standards, and emphasizing my need to acquire more 'skills' in order to feel able to provide Joe with the care that he needed.

As a result of these co-constructing factors, I have suggested that a philosophy of HIV nursing care could be developed in order to inform HIV nursing practice. Central to this philosophy is patient-centred care and non-judgmental care, which then enables the disclosure of concerns to take place. The care that is delivered within the philosophy is heavily influenced by the nurse's way of being. Therefore the nurses' way of being is central to the delivery of patient-centred care within HIV nursing.

Moving forward, identifying how the nurses' way of being affects the care that is delivered can then be translated into patient-centred care. This will help HIV nurses articulate what factors contribute to the care they provide, as reflected within the HIV person-centred nursing framework. Constructing this philosophy based on the data helps identify how HIV nurses elicit patient concerns.

6.5.4: What are the key implications of the findings for the wider nursing agenda

Within the previous sections I have discussed what the key implications of my research findings are with regards to HIV nursing, relating to self awareness,

reflection within clinical practice and developing a HIV person centred nursing framework. I also established that my research adds to the current body of knowledge on HIV nursing as it explores the positive aspects of providing care for people living with HIV; and how as a result of the nurses' different ways of being, concerns can be expressed by the patient in order for PCC to be delivered.

I will now go on to discuss how my research findings can add to discussion within the wider nursing agenda. Within the nursing profession there are significant issues with regards to the recruitment and retention of nurses. Based on my research, I would suggest that the process of recruiting nurses should take into consideration, who the nurse is as a person. With this in mind, nurses need to be supported to have a greater insight into how they function as a nurse and the impact that their behaviour can have on the care that is being delivered.

How we train pre-registration and post registration nurses with regards to communication skills needs to be considered in line with the research findings. As my research has highlighted, communication skills training only goes some way in the process of enabling the nurses to elicit patients' concerns. As previously mentioned we spend a considerable amount of time exploring the functionality of communication with regards to the nurses' ability to gather information from patients and very little time exploring how nurses learn to relate to patients. Unless the nurse can relate to the patient then any skills that have been taught will not be able to be utilised by the nurse. Training programmes should therefore explore the unique aspect of 'being a nurse' and how these experiences help shape nurses' ability to learn from patients and in doing so elicit their concerns.

There needs to be greater support in place for nurses to access clinical supervision when dealing with complex patients. This is currently not widely available for all

nurses and should be viewed as a necessity, rather than a luxury. I have demonstrated with my research the significance of patients' stories on the nurse and how these stories can shape future care relationships (through my own story of Joe and with the stories that have been shared by the participants). Therefore nurses should be provided with a safe space to explore the significance of these patients' interactions in order to provide positive outcomes for patients. In order for this to happen the Nursing and Midwifery Council (NMC) needs to develop policies at a national level, to ensure that clinical supervision becomes a mandatory requirement for nurses, such a move would be in line with other professions, such as Clinical Psychologists and Counsellors.

Person Centred Healthcare (PCH) can be viewed as the most compassionate and intuitively right way to practice clinically. There is an increase in health literacy and patients' increasingly have a deeper understanding of their illness, which influences treatment choices. The current notion of value in healthcare is demand lead, supply driven. In the NHS's pursuit for cost effective care and best clinical outcomes for patients, care has been driven by the lowest financial cost. In light of this current trend in healthcare delivery, in order to prevent suboptimal patient outcomes healthcare policy needs to establish what good care looks like and what is meant by the term value and how this is then measured.

6.6: Summary

I have suggested that HIV nurses need to be self-aware in order to provide patient-centred care. I have suggested that a way to develop this awareness would be by exploring ways to develop self-awareness, and proposed that reflective practice or Schwartz center rounds could facilitate this in clinical practice. I have proposed the idea of developing a HIV person-centred nursing framework. This framework

encourages nurses to develop their way of being within the therapeutic relationship in order to facilitate the disclosure of patient concerns, enabling PCC to be delivered.

7. Happy Endings

Joe had been transferred from the hospital to a care home, at his request, so he could receive the end of life care that he needed.

I had been asked to attend the care home where Joe was staying for a care review to ensure his needs were being met. As I arrived I walked past Joe's room to see him holding court, propped up in bed with his sister sat at the side of him and a gentleman that Joe had previously shown me in a photograph and explained that he was an old friend and catholic missionary.

I stood at the door of Joe's room and waved. I didn't attempt to go in as I was running a little late for the care review.

Joe: 'Here she is. They are waiting for you so they can start. We're having all our sins absolved...in here... it's great. I would invite you in to join the party...but he is not a fucking magician'.

I snigger and feel like a teenager in a joke that the grown ups don't appreciate. I notice that his sister and friend were looking down at the floor, not quite knowing what to do.

Joe proudly introduces me as his nurse and informs his audience that he has inspired me to develop lots of different projects to help nurses to take better care of others like him. This makes both of us smile.

Me: 'This is true, my lord. I am the nurse I am today because of you and all the experiences we have shared'.

Joe: 'Awwh that's lovely of you to say Chelle ... I hope Gary and Laura (the other HIV specialist nurses within the team) appreciate all the hard work that has gone into you'.

I think at this point if his sister and friend could have crawled out of the window with embarrassment they would have done. I laugh and promise to come back and see him after the care review.

After the care review, I return to Joe, as promised to explain what had been said. As I approach the room I see he is now alone, still propped up in bed listening to music. I give Joe an overview of the meeting and he seems pleased that his pain relief is going to be increased.

Joe: 'I'm lucky to have you ... if I had another nurse, I might have ended up as a file on their desk ...'

This made me think of my own desk, and the medical files that were currently on it, which, to the untrained eye, were just sets of notes containing information, not people and their stories. I am still thinking about this image of people's lives being files on my desk when I hear music playing and Joe singing: 'Wake up and stumble on my life, can't get no love without sacrifice, if anything should happen, I guess I wish you well, a little bit of heaven and a little bit of hell'.

At first I am not sure what he is singing and then it hits me, along with a wave of emotions. It's a song called 'Happy Ending' by Mika.

Joe begins to sing louder as he turns up the volume on his stereo:

'This is the hardest story that I've ever told
No hope, no love, or glory
Happy endings gone forever more
I feel as if I'm wastin'
I'm wastin' everyday
This is the way you left me,
I'm not pretending.
No hope, no love, no glory
No happy ending.
This is the way that we love,
Like it's forever.
Then live the rest of our life,
But not together'.

Joe breaks from singing and turns the music down.

Joe: 'I knew that this would make you cry ... I wanted this as my last song as I left the church... I knew you would get the meaning behind this song ... it means a lot that you care "

Distracted by the song and almost on cue, Joe sings in a very high pitch voice, whilst making a mouth shape with both his hands, which is what happens at this point in the music video to the song.

Joe motions the lyrics : 'a little bit of love, little bit of love, little bit of love, little bit of love'

Joe: " Awhh Croston ... are those genuine heartfelt tears...We have had some great times, Croston, but my work with you is done ... you'll be successful in all you do and

I am happy that I have somehow shaped that'. Still talking to me through the mouth shape he has made with his hands.

By this point I am a wreck and the tears are falling freely. I am trying really hard to regain some kind of composure. There is so much to process and I can't make sense of what Joe is saying. I am also trying to process the powerful words that he is singing. What is he trying to tell me? Is he talking about the HIV, his sexuality or his interpersonal relationships? My head is spinning as I try to make sense of what I am listening to. I want to understand him and the meaning behind the song but it feels too hard and confusing. I wanted Joe to answer my questions about what he was referring to HIV, sexuality, relationships or something else? I can almost hear his playful response: 'Tick all that apply'. I didn't ask and just listened.

Feeling overwhelmed and trying hard to regain my composure, I hear Joe loud and clear as he brings me back to the here and now.

Joe : 'Come on Croston ...it's a party... Celebrate good times ...come on!!! ,With this he switches the CD to Kylie Minogue's 'Celebration' and begins to sing along, waving his hands above his head in time to the music, until I reluctantly join in.

I leave shortly after with the words of Mika's song being played over and over again in my head: 'This is the way you left me, I'm not pretending. No hope, no love, no glory, no happy ending'.

7.1 Future Research

In order to expand my research findings I would like to explore the clinical learning experiences of undergraduate student nurses in relation to caring for PLHIV. HIV is becoming a chronic manageable condition and patients are living longer. As a result of advances in HIV treatment PLHIV will be cared for in non-specialist units.

I would be interested in hearing undergraduate nurses' stories in relation to caring for PLHIV, exploring how they develop empathy and provide patient-centred care to this cohort of patients. Within the study I would like to discuss the relationship between emotions, self-awareness and the development of compassionate care. I would be interested to explore what factors enabled the students to provide authentic care to PLHIV and in doing so ascertain the role of specialist nurses in this process as well as the role of nurse education.

7.2 Reflections on the Research Process

No research is entirely flawless (Sandelowski 1986). My research examined the phenomena of the nurse-patient relationship within HIV care, from the nurse perspective and therefore did not explore the phenomena from the patients' perspective. This is problematic as the therapeutic relationship is reciprocal, and therefore a key element to understanding this relationship (the patients' perspective) was missing within the research. Within the research, through the participants' transcripts and the use of storytelling, we get a sense of what the therapeutic relationships were like and how these developed. Due to the methodology used these findings are not generalizable to all populations where PLHIV and formal carers interact (and may be linked to a specific time period) but do offer an insight and the opinions given by the participants are supported by a priori knowledge (Mason 1996). The method of data collection, interviewing has been identified as a limitation. Ideally a more combined approach of interviews and observations would have been used to

witness the relationships that had been developed in order to observe the therapeutic relationship as it developed (Field & Morse 1985). In relation to the study findings, a significant factor that was not addressed, was how the HIV nurses developed the self-awareness they alluded to within the interviews. If I was able to return to the participants or if I were to repeat the research, I would further explore what factors had enabled them to develop self-awareness. I would utilize some of the theories that I have already previously mentioned in order to conceptualize what being self-aware means in the context of HIV nursing.

7.3 Concluding Thoughts

The final chapter presents my concluding thoughts and reflections on the study. My study began, based on practice-based observations concerning : the change in patients' needs as a result of HIV treatment advances, the treatment of HIV becoming less medically complicated, and the focus of consultations shifting to explore how patients were living with HIV. This change in patients' needs resulted in an increase in my workload, with patients requiring more emotional and psychological support. Through this observation, I wanted to explore ways that would ensure that other practitioners would provide similar emotional and psychological support for patients accessing clinic. This resulted in my interest in providing patient-centred care. I had initially thought the way to ensure that this was implemented in practice was through developing practitioners' skills. As a result of undertaking the study it became apparent that my way of being had a significant impact on my ability to provide emotional and psychological support. Thinking back to my initial observation that had triggered my research, perhaps other healthcare professionals' ways of being affected the process of providing this type of support for patients, as opposed to a skill deficit that I initially assumed.

In order to investigate how HIV nurses elicited patients' concerns I used IPA as a

methodology for the study design. As a researcher the way IPA was explained by Jonathan Smith, the 'founder' of the approach, was appealing. The approach to research seemed logical and user friendly, particularly the guidance around data analysis. Prior to embarking on my study I had a good theoretical understanding of IPA as a research tradition that I had gained from reading Smith's work, numerous research papers and theses that had used this methodology, and I felt confident that the design best met my study's objectives. I drew particularly on Eatough and Smith (2006), Bramely and Eatough (2005) and Robinson (2002).

As my research began to unfold I realized that although my study had been heavily designed utilizing an IPA approach there was something missing when it came to the data analysis. The suggested format of data analysis, that was once appealing and seemed user friendly, was in reality confusing, labour intensive and time consuming. Using the IPA approach to data analysis, I felt, explained my findings, but lacked, another layer that needed to be uncovered in order to reach a deeper understanding. Unsure of what this might be, I returned to my supervisors and the literature for guidance.

To my astonishment, I began reading and enjoying the work of Heidegger. This process was initially very challenging and required me to immerse myself in his work, and critiques of his work. At times I thought I would never understand his philosophy and was tempted to resign myself to giving it up as a bad job. Through sheer determination and a desire to produce the best piece of work I could, I finally began to understand the significance of his work in relation to my own. So much so, I passionately began to inform my fellow HIV nursing colleagues just how much Heideggerian philosophy was in line with our practice. My peers humored me whilst I explained, looking at me initially as if I had gone mad or been possessed by an academic. Eventually, through my passionate recollection of Heidegger's theories

and explaining my findings alongside Heidegger's thoughts on being, (in a somewhat eccentric mad professor way scribbling diagrams to explain links to tricky concepts) even the critic in the room had a light bulb moment as they began to see how their practice incorporated Heidegger's philosophy; and this understanding of his work could aid practice development.

Heidegger's philosophy enabled me to deepen my understating of the HIV nurses' way of being and led me to a different way of thinking. This then triggered me to explore the wider literature on authenticity, which provided food for thought as I began to understand the complexities involved within the nurse-patient relationship.

Exploring the literature on the nurse-patient relationship alongside my findings increased my desire to want to explore the HIV nurses' way of being further. This interest made me consider the role of self-awareness in the process of developing the therapeutic relationship and subsequent care that followed.

Within the study I presented my findings using superordinate themes, which is in line with the tradition of IPA. Within the findings section there is clear demonstration from the patient stories, and the reflexive nature of the participants, that this process of developing the therapeutic relationship ultimately enabled the nurses to practice PCC.

My findings were surprising, as they did not reveal the practical skills I hoped to uncover. Instead, they enabled me to explore a way of being that the HIV nurse had in order to elicit patients' concerns. I had initially hoped that I would be able to use these findings in order to improve a communication course that I had developed. This new way of thinking enabled me to explore the importance of the nurse patient relationship and how it contributes to patient-centered care. As a result of

undertaking this process, I suggested a HIV nursing philosophy of care as a way of enabling HIV nurses to develop therapeutic relationships.

This work adds to the body of knowledge by providing an in depth analysis of ten HIV nurses' stories and in doing so highlights the importance of authenticity in the therapeutic relationship. Within the participants' stories it offers an insight into how HIV nurses facilitate patient-centered care. The research therefore can be used to add to the knowledge on HIV nurses' practice and how this contributes to patient outcomes.

As a HIV nurse, a research student and colleague to some of the participants within the study, it was important that I was aware of the influences that these roles had on the development of this thesis. Throughout the thesis I have shared stories from my own practice that have helped to shape the thesis and facilitated a deeper understanding of the findings. On reflection my experiences and perspectives have been inspirational to me throughout the research process and fundamental to this thesis.

Patient-centred care is thought to be the holy grail of practice as healthcare becomes increasingly more technical with fast turn-overs. High demand on services mean that there is a danger that PCC will be viewed as a luxury and not a necessity.

As HIV care moves towards a chronic manageable disease area, service delivery is changing, with patients accessing services delivered by different providers in order to meet their healthcare needs. Despite these disease area changes the nurse's role within this process remains central in providing non-judgmental, stigma free, patient-centred care in order for patients to experience positive health outcomes.

Reference list

Adebajo SB , Bamgbala AO, Oyediram MA (2003) Attitudes of health care providers to persons living with HIV/AIDS in Lagos state, Nigeria *African journal of reproductive health* 7, 103-112

Aiken M (1996) *The professional stranger: An informal introduction to Ethnography*, Academic Press, San Diego, CA

Allen-Collinson J (2009) Sporting embodiment in sport sciences and (continuing) promise of phenomenology, *Qualitative Research in Sport Exercise*, 1,(3), 279-296

Antiretroviral Therapy Cohort Collaboration (2008) Life expectancy of individuals on combination antiretroviral therapy in high-income countries: a collaborative analysis of 14 cohort studies, *Lancet* 372, 293-9

Anderson R , Funnell M , (2005) Patient empowerment : reflections on the challenge of fostering the adoption of a new paradigm, *Patient Education and Counseling* 57, (2), 153-7

Anderson R, Funnell M (2010) Patient empowerment: Myths and misconceptions, *Patient Education and Counseling* 79, (3), 277-282

Annells M (1996) Hermeneutic phenomenology philosophical perspectives and current use in nursing research *Journal of advance nursing*, 23,4, 705-713

Aranda S, Street A (1999) Being authentic and being chameleon like: Nurse-patient interaction revisited: *Nursing inquiry*, 6 (2) 75-82

Attard J, Baldacchino D (2014) Nurses and Midwives' acquisition of competency in spiritual care: A focus on education, *Nurse Education Today*, 34, (12), 1460-1466

Balabanova Y, Coker R, Ayun RA, Drobiniewski F (2006) Stigma and HIV infection in Russia, *AIDS Care* , 18, 846-852

Ballinger C (2004) Writing up rigour: responding and evaluating good scholarship in qualitative research: *British Journal of Occupational Therapy*, 67 (12) 540-546

Barbour RS (1993) 'I don't sleep with my patients – do you sleep with yours?': Dealing with staff tensions and conflict in AIDS related work. In *Aids related work: AIDS: facing the second decade* (Aggleton P, Davies P, Hart G eds), The Falmer Press, London 159-168

Barnett R (2007) *A will to learn: being a student in an age of uncertainty*. Maidenhead: The Society for Research in Higher Education and Open University Press

Basavaraj K H, Navya MA, Rashmi R (2010) Quality of life in HIV/AIDS *Indian L Sex Transm Dis*, 31, 75-80

Baykin A, Schoenhofer S (2001) *A model for transforming practice*, Jones and Bartlett Publishers International, London.

Bing EG , Burnham AM, Longshore D et al (2001) Psychiatric disorders and drug use among human immunodeficiency virus-infected adults in the United States, *Archives of General Psychology*, 58, 721-728

Blank A, (2011) "It's not just about the money": the meaning of work for people with severe and enduring mental health problems – an interpretative phenomenological analysis. PhD thesis: Brunel University

Boud D, Keogh R, Walker D (1985) *Reflections: turning experiences into learning*. Kogan page, London.

Boughan J, Smith A (2009) *Caring in nursing practice*, Pearson education LTD, Harlow

Boykin A, Schoenhofer S (1993) *Nursing as caring: A model for transforming practice*, National league for nursing press, New York

Boykin A ,Schoenhofer S (2001) *Nursing as caring: A model for transforming practice*, Sudbury Mass Jones, Jones and Barlett Publishers

Brannen J (1988) The study of sensitive subjects, *Sociological review*, 36, 552-563

Bramley L (2014) 'How does it really feel to be in my shoes?' *Journal of clinical nursing*, 23, (19), 2790-2799

Bramley N, Eatough V (2005) The experiences of living with Parkinson's disease : An interpretative phenomenological analysis case study *Psychology and Health* 20 (2) 223-235

Brewer JD, Hunter A (2006) *Foundations of multi-method research synthesizing styles*, Sage Publications, California.

British HIV Association (2013) *British HIV association standards of care for people living with HIV*, Mediscript.

British Psychological Society, British HIV Association & Medical Foundation for AIDS & Sexual Health (2011) *Standards for psychological support for adults living with HIV*. London: MedFASH

Butler-Kisber L (2002) Artful portrayals in qualitative inquiry. The road to found poetry and beyond *Alberta Journal of Educational research*, 48,(3), 229-239

Burnard P (1996) *Acquiring interpersonal skills: A handbook of experiential learning and healthcare professionals*, 2nd edition, London, Chapman and Hall

Burnard P (2003) Ordinary chat and therapeutic conversation: phatic communication and mental health nursing. *Journal of Psychiatric and Mental health nursing*, 10, (6), 678-682.

Castro A, Farmer P (2005) Understanding and addressing AIDS stigma: from anthropological theory to clinic practice in Haiti, *Am J Public Health* 95, (1) 53-9

Cao X, Sullivan SG (2006) Understanding HIV –related stigma and discrimination in a ' blameless' population *AIDS education and prevention*, 18, 518

- Chant S, Jenkinson T, Randle J, Russell G,(2002) Communication skills: some problems in nursing education and practice, *Journal of clinical nursing*, 1, 12-21
- Ciesla J, Roberts JE (2001) Meta-analysis of the relationship between HIV infection and risk of depressive disorders. *American Journal of Psychiatry*, 158, 725–730.
- Coffey A, Atkinson P (1996) *Making sense of qualitative data: contemporary research strategies*, Thousand Oaks , CA, Sage
- Colbarriell L, Squae M (2005) The culture of cancer and therapeutic impact of qualitative research interviews, *Journal of research in nursing*, 10, (5), 551-567
- Collins J and Selina H (1998) *Heidegger for beginners*. Cambridge: Icon Books.
- Collins K, Nicholson P (2002) The meaning of ‘satisfaction’ of people with dermatological problems: reassessing approaches to qualitative health psychology research, *Journal of health psychology*, 7, 5 615-629
- Collins S (2009) Good communication helps to build a therapeutic relationship, *Nursing Times*, 105, (24), 11, June
- Connolly M, Perryman J, Mckenna Y, Orford ,Thomson L, Shuttleworth J, Cocksedge J (2010) SAGE and THYME: A training model for training health and social care professionals in patient focused support, *Patient education and counseling*, 79 87-93
- Corey G, (1982) *Theory and practice of counseling and psychotherapy*, Monterey, CA :Brooks/Cole
- Corless IB , Voss J, Guarino AJ, Wantland D, Holzemer W, Hamilton M , Sefcick E , Willard S , Kirksey K, Portillo C, Rivero Mandez M, Rosa ME, Nicholas PK, Human S, Maryland M, Moezzi S, Robinson L, Cuca Y (2013) The impact of stressful events , symptom status and adherence concerns on quality of life in people living with HIV *J Assoc Nurses AIDS care*, 24, 478-90
- Coward M (2011) Does the use of reflective models restrict critical thinking and therefore learning in nurse education?,*Nurse Education Today*, 31, (8), 883-886
- Creswell J (2012) *Qualitative inquiry and research design: Choosing among five approaches*, 3rd edition, Sage Publications, London.
- Croft M (1996) *Phenomenology and nursing research*, Melbourne Churchill Livingstone
- Croston M, Petrak J, Ustainowski A (2017) Use of the wellness thermometer to improve consultations for patients with Human Immunodeficiency Virus, *Nursing Standard*, 31,(41), 46-53
- Dahlberg K (2006) ‘The individual in the world – the world in the individual’ Towards a human science phenomenology that includes the social world. *Indo-Pacific journal phenomenology*, 6 (Spec .ed.) 1-9
- Dahlberg K, Dahlberg H, Nystrom M (2008) *Reflective life world research*, Second edition, Hungary Student literature

Dart AM (2011) *Motivational interviewing in nursing practice: empowering the patient*, Jones and Bartlet, London

Deacon H, Stephney I, Prosalendis S, (2005) *HIV/AIDS stigma: a theoretical and methodological analysis*. Cape Town: HSRC Press.

Dean S , Smith J , Payne S (2006) Lower back pain: Exploring the meaning of exercise management through interpretative phenomenological analysis, *In Qualitative research for allied health professionals : Challenging choices* , Whurr publishers limited, Chichester, 139-155

Degroote S, Vogelaers DP, Vermeir P, Mariman A, De Rick A, Van Der Gucht B, Pelgrom J, Van Wanzele F, Verhofstede C, Vandijck D M (2013) Socio economic , behavioural (neuro)psychological and clinical determinants of HRQol in people living with HIV in Belgium: a pilot study *J Int AIDS Soc*, 16 18643. 1-8

Del Rio CM, White LJ (2012) Separating spirituality from religiousity: A hylomorphic attitudinal perspective. *Psychology of Religion and Spirituality*, 4, (2), 123

De Lucio LG, Lopez FJG, Lopez MTM, Hesses BM, Caamano MDC (2000) Training programme in techniques of self-control and communication skills to improve nurses relationships with relatives of seriously ill patients: A randomized controlled study . *Journal of Advanced Nursing*,32,2,425-431.

Denzin NK (1997) *Interpretive ethnography: Ethnographic practices for the 21st century*. Thousand Oaks, CA: Sage.

Department of Health (DH) (2014) *Five years forward*. The Stationery Office (TSO), London

Department of Health (DH) (2013) *The Francis report* . The Stationery Office (TSO), London

Department of Health (DH) (2011) a. *Healthy Lives, Healthy People: our strategy for public health in England*. The Stationery Office (TSO), London.

Department of Health (DH) (2011) b. *No health without mental health: a cross-government mental health outcomes strategy for people of all ages*. The Stationery Office (TSO), London.

Department of Health (DH) (2000) *The NHS plan: A plan for investment a plan for reform*. The Stationery Office (TSO), London.

Department of Health (DH) (1997) *The New NHS modern and dependable*. The Stationery Office (TSO), London.

Devereux G (1967) From anxiety to Method in the behavioral sciences : In Pearson P and Rowan S (eds) *Human inquiry –A source book of new paradigm research* , Chichester, Wiley.

Devisser R, Smith JA (2006) Mister in between , A Case study of masculine identity and health related behavior, *Journal of Health Psychology* 11 (5) 685-695

DeVito JA (2007) *The interpersonal communication book* 11th edition, London , Pearson Education.

- Dewey J (1938) *Experience and education*. New York, NY Collier
- Dewey J (1929/1958) *Experiences and Nature*. Dover Publications inc, New York, NY Collier
- Dewing J (2002) From ritual to relationship: a person centered approach to consent in qualitative research with older people who have dementia, *Dementia*, 1, 157-171
- Dickson A, Knussen C, Flowers P (2008) 'That was my own life; it's almost like a past life now' identity crisis, loss and adjustments amongst people living with chronic fatigue syndrome. *Psychology and Health* 23,(4) 459-476
- Dilthey W (1977) *Descriptive psychology and historical understanding*, Zanner RM and Heiges KL, Trans *The Hague :Martinus Nijhof* (Original work published in 1894,1910)
- Dingwall R and Allen D (2001) The implications of healthcare reforms for the profession of nursing *Nursing Inquiry* 8, (2), 64-74
- Doyle D, Copeland H, Bush D, Stein L, Thompson S (2011) A course for nurses to handle difficult communication situations: A randomized control trial of the impact on self-efficacy and performance, *Patient education and counseling*, 82,100-109.
- Draucker C (1999) The critique of Heideggerian hermeneutical nursing research. *Journal of Advance Nursing* 30, 12, 360-373
- Dreyfus HL (2000) Husserl, Heidegger and modern existentialism, In Magee M (ed) *The great philosophers*, Oxford OU Press.
- Dunkel J, Hatfield S (1986) Counter transference issues in working with people with AIDS, *Social work*, 31, 114-117
- Eatough V , Smith JA (2006 a) I feel like scrambled egg in my head. An idiographic case study of meaning making and anger using interpretative phenomenological analysis, *Psychology and Psychotherapy, Theory, Research and Practice* 79,115-135
- Eatough V, Smith J (2006b) I was like a wild wild person: understanding feelings of anger using interpretative phenomenological analysis, *British Journal of psychology*, 97, (4), 483-498
- Eckroth-Bucher M, (2010) Self awareness: A review and analysis of a basic nursing concept, *Advances in Nursing Science*, 33, (4), 297-309
- Ely M (2007) In-forming re-presentations In Clandinin DJ (ed) *Handbook of narrative inquiry, mapping methodology* (pp 567-598), Thousand island oaks, CA : Sage
- European Union (EU)(2004) Enabling good health for all: A reflection process for a new EU strategy. Available on line at last accessed march 2017
http://ec.europa.eu/health/ph_overview/Documents /bryne_reflection_en.pdf
- Faden R, Beachamp T (1986) *A history and theory of informed consent*, Oxford University Press, New York

- Falk- Rafael A (2001) Empowerment as a process of evolving consciousness: A model of empowered caring, *Advances in Nursing science*, 24 (1), 1-16
- Faulkner A (1990) Teaching interaction skills. Chapman &Hall, London.
- Faulkner SL (2005) Method poems, *Qualitative Inquiry*, 11(6), 941-949
- Fellowes D, Wilkinson S, Moore P (2004) Communication skills training for health care professionals working with cancer patients and their families and/or carers. Cochrane Collaboration
- Field PA, Morse JM (1985) *Nursing Research: The Application of Qualitative Approaches*. Croom-Helm, London
- Finlay L (2003) Through the looking glass: Intersubjectivity and hermeneutic reflection. In Finlay L and Giugh B (Eds) *Reflexivity: A practical guide for researchers in health and social sciences*, Oxford: Blackwell.
- Finlay L (2008) A dance between the reduction and reflexivity: Explicating the 'phenomenological attitude' *Journal of Phenomenological Psychology*,39,1-32
- Firth – Cozen J, Cornwall J (2009) *Enabling compassionate care in acute hospital trusts*, London , The King's fund, London.
- Fletcher C , Baldry C (2000) A study of individual differences and self awareness in the context of multi-source feedback, *Journal of Occupational and Organizational Psychology*, 73, 3 303-319
- Flowers P (2008) Temporal tales: The us of multiple interviews with the same participant. *Qualitative Methods in Psychology Newsletters*,5, 24-27
- Florum –Smith A, (2012) Exploring the concepts of HIV stigma, *Nursing Forum*, 47, (3), 153-165
- Forde A (2011) 'Evolutionary theory of mate selection and partners of transpeople: A qualitative study using interpretative phenomenological analysis ' *The qualitative report* (2011) 16,5 1407-143
- Francis R (2013) The Mid Staffordshire NHS foundation trust public inquiry, *The National archives*.<http://www.midstaffpublicinquiry.com/report>
- Freshwater D, Stickley T (2004) The heart of art: emotional intelligence in nurse education, *Nurse Inquiry*, 11, 2, 91-8
- Friedland GH, Williams A (1999) Attaining higher goals in HIV treatment: the central importance of adherence, *AIDS*, 13, S61-72

- Funnell MM, Anderson RM, Arnold MS (1991) Empowerment: An idea whose time has come in diabetes education, *Diabetes Educator*, 17, 37-41
- Furman R (2006) Poetic forms and structures in qualitative health research, *Qualitative research* 16, 4, 560-566
- Gair S (2002) In the thick of it: A reflective tale from an Australian social worker/ qualitative researcher, *Qualitative health research*, 12, 1, 130-39
- Gastmans c (1998) Interpersonal relations in nursing: The philosophical-ethical analysis of the work of Hildegard Peplau, *Journal of advanced Nursing*, 28, 1312-1319
- Geanollos R (1998) Hermeneutic philosophy part 2, a nursing research example of the hermeneutic imperative to address for structures/pre structures, *Nursing Inquiry* 5, 4 238-247
- Gibbs G 1998 *Learning by doing: A guide to teaching and learning methods*, Oxford , Oxford Polytechnic further education unit.
- Giddings L, Grant B, (2006) Mixed methods research for the novice researcher *Contemporary nurse* 23,1, 3
- Giorgi A (1997) The theory, practice and evaluation of the phenomenological method as a qualitative research procedure *Journal of Phenomenological Psychology* 28 (2) 235-260
- Giorgi A (2010) Phenomenology and the practice of science, *Existential Analysis*, 21, 1, 3-22
- Giorgi A (2011) IPA and science: A response to Jonathon Smith, *Journal of phenomenological psychology*, 42,195-216
- Glense C (1997) That rare feeling 're presenting research through poetic transcription , *Qualitative Inquiry* 3,202-222
- Godin G, Cote I, Naccache H, Lambert L, Trothers S (2005) Prediction of adherence to antiretroviral therapy : At one year longitudinal study. *AIDS Care: Psychological and socio-medical aspects of HIV/AIDS*, 17, 4, 493, 504
- Goffman E (1963) *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ, Prentice-Hall
- Goldkuhl E (2012) Pragmatism v's interpretivism qualitative information systems research, *European Journal of Information Systems*, 21, 2, 135-146.
- Goodrich J (2011) Schwartz center rounds:Evaluation of the UK pilots. The Kings Fund , London.
- Gray M (1994) Personal experiences of conducted interviews, *Nurse Researcher*, 1 (3) 65-71
- Gray JG (2004) *Introduction in Heidegger What is called thinking?* Gray GJ translation New York Harper Perennial

- Guba EG (1990) *Paradigm dialogue*. London, Sage Publications
- Guba EG, Lincoln YS (1989) *Fourth generation evaluation*, London, Sage
- Guignon CB (1993) *The Cambridge Companion to Heidegger* Cambridge University Press
- Hadfield J, Brown D, Pembroke L, Hayward M (2009) Analysis of accident and emergency doctors responses to treating people who self harm, *Qualitative, Health Research*, 19, 755-765
- Hammersley M, Atkinson A (2007) *Ethnography: Principles in practice*, Routledge, London.
- Harding R, Lampe FC, Norwood S (2010) Symptoms are highly prevalent among HIV outpatients and associated with poor adherence and unprotected sexual intercourse. *Sexually Transmitted Infections*, 86, 520–524.
- Hargie O (2006) *The handbook of communication Skills* 3rd edition, London, Routledge.
- Hayter M (1999) Burnout and AIDS care related factors in HIV community Clinical Nurse Specialists in the North of England *Journal of Advanced Nursing* 29 (4), 984-993
- Hodgson I (2006) Empathy, inclusion and enclaves: the culture of care of people with HIV/AIDS and nursing implications, *Journal of Advanced Nursing*, 55, (3), 283-290
- Hodgson I, HIV Stigma ;A question of morality ? *HIV Nursing*, 7, 3, 4-6
- Hodgson I, Ross J, Hoamujompa C, Gitaumburu D (2012) Living as an adolescent with HIV in Zambia- Lived experiences , sexual health and reproductive needs, *AIDS care* , 24, (10), 1204, 1210
- Hess R F , Mckinney D (2007) Fatalism and HIV/AIDS beliefs in rural Mali, West Africa, *Journal of Nursing Scholarship*, 39, 113-118
- Herdman EA (2004) Nursing in a postmotional society, *Nursing Philosophy*, 5, (2), 95-103
- Ingram T (2009) Compliance: A concept analysis, *Nursing Forum*, 44, 189-194
- Inwood M (1997) *Heidegger a very short introduction*. Oxford: Oxford University Press.
- International Council for nurses (2003) *Nurses fighting AIDS stigma, caring for all*. International Council of Nurses, Geneva
- Institute of medicine (2001) *Crossing the quality chasm*, Washington DC: National Academies press
- Jack K, Miller E (2008) Exploring self awareness in mental health practice, *Mental health practice* 12, (3), 31- 35

- Jack K, Smith A (2007) Promoting self awareness in nurses to improve nursing practice, *Nursing standard*, 21, (32), 47-52
- Jack K , Wibberley C (2014) The meaning of emotion work to student nurses: A Heideggerian analysis, *International Journal of nursing studies*, 51, 900-907.
- Jarvis P (1987) *Adult learning in the social context*, Croom Helm , London.
- Jeffries IV, W.L., Townsend, E.S., Gelaude, D.J., Torrone, E.A., Gasiorowicz, M. and Bertolli, J., 2015. HIV stigma experienced by young men who have sex with men (MSM) living with HIV infection. *AIDS Education and Prevention*, 27(1), pp.58-71
- Jenk C (2011) *Transcribing talk and interactions, issues in representation of communication data*, John Benjamins publishing company, London.
- John CC (1994) *The Burford NDU model: Caring in practice*, Blackwell Science.
- Jones EE , Farnia A, Hastorf AH, Markus H, Miller DT, Scott RA (1984) *Social stigma: The psychology of marked relationships*, New York, W.H Freeman
- Kalisch BJ (1997) What is empathy? *American Journal of Nursing*, 73, 1548-1552
- Kirk TW (2007) Beyond empathy, clinical intimacy in nursing practice, *Nursing Philosophy*, 8, (4), 233-243, Oct
- Kitwood T, (1997) On being a person. In *Dementia Reconsidered: The person comes first*, Kitwood et al., ed , Open University press.
- Kloppenbergt JT (1996) Pragmatism: an old name for some new ways of thinking, *The Journal of American History*, 83, 100-138
- Knussen C, Niven CA (1999) HIV AIDS and healthcare workers: Contact with patients and attitudes towards them, *Psychology and Health* 14, (3), 367-378
- Koch T (1995) Interpretative approaches in nursing research, the influence of Husserl and Heidegger *Journal of advanced nursing* 21, (5), 827-836
- Koch T (1996) Implementation of a hermeneutic inquiry in nursing: Philosophy, rigour and representation *Journal of advanced nursing*, 24, (1) , 174-184
- Kruijver PPM, Kerkstra A, Francke AL, Bensing JM, Van del Wiel HBM (2000) Nurse patient communications in cancer care. A review of the literature, *Cancer nursing*, 23, (1), 20-31.
- Langridge D (2007) *Phenomenology psychology: Theory, Research and method*, Harlow, Pearson
- Lauer DR, Ward SE, Heidrich SM, Keller ML, Bowers BJ, Brennan PE , Wells TJ (2002) Patient centered interventions, *Research in nursing and health* 25, 246-255
- Laws MB, Rose GS, Bezreh T, Beach MC, Taubin T, Kogelman L, Gethers M, Wilson IB (2012) Treatment acceptance and adherence in HIV disease: patient identity and the perceived impact of physician- patient communication *Patient Preference Adherence*, 6, 893-903

- Larkin M, Eatough V, Osborn M (2011) Interpretative phenomenological analysis and embodied, active, situated cognition, *Theory and psychology*, 21, 3, 318-332
- Laryea M, Gien L (1993) The impact of HIV positive diagnosis on the individual , Part 1: stigma, rejection and loneliness, *Clinical nursing research* , 2, 245-263
- Lepelge A, Gzil F, Cammelli M, Lefevre C, Pachoud B, Vile I (2007) Person centeredness : Conceptual and historical perspectives, *Disability and Rehabilitation*, 29, 1555-1565
- Lipkin M, Quill TE, Napodano RJ (1984) The medical interview: A core curriculum for residencies in internal medicine, *Annals of International Medicine*, 100, 277-284
- Lohrmann C, Valimaki M, Muinonen U, Dassen T, Peate I (2000) German nursing students knowledge of and attitudes to HIV and AIDS: two decades after the first AIDS cases. *Journal of Advanced Nursing*, 31,(3), 696-703
- Long T, Johnson M (2000) Rigor, reliability and validity in qualitative research, *Clinical Effectiveness in nursing*, 4, 30-37
- Lown B, Manning C (2010) 'The Schwartz center rounds: Evaluation of an interdisciplinary approach to enhancing patient centered care, teamwork and provider support' *Academic Medicine*, 85. (6). 35-40
- Madison DS (1991) 'That was my occupation': Oral narrative, performance, and black feminist thought *Text and performance quarterly*, 13, 213-232
- Mahajan AP, Sayles JN, Patel VA, Remien RH, Sawires SR, Ortiz DJ, et al (2008) Stigma in the HIV/AIDS epidemic: a review of the literature and recommendations for the way forward *AIDS*, 22 (suppl 2) s67-79
- Mannheimer SB, Matts J, Telzak E , Chesney M, Child C, Wu AW, Fieldland G (2005) Quality of life in HIV-infected individuals receiving antiretroviral therapy is related to adherence *AIDS Care*, 17, 10-22.
- Martin DJ, Garske JP, Davies MK (2000) Relation of therapeutic alliance with outcomes and other variables: A meta-analytic review *Journal of Consultant Clinical Psychology*, 68, 438-450
- Masterson-Allen S, Mor V, Laliberte L, Montiero L (1985) Staff burnout and in hospice settings *Hospice Journal* 1, 1-15
- Matta SM (2006) Re-thinking empathy in nursing education: shifting to a developmental view, *Nursing Philosophy*, 7, (1), 3-10, Jan
- Mburu G et al. *Journal of the International AIDS Society* 2013, 16(Suppl 2):18636
<http://www.jiasociety.org/index.php/jias/article/view/18636> |
<http://dx.doi.org/10.7448/IAS.16.3.18636>
- McCance T V, McKenna HP, Boore JRP (1999) Caring: theoretical perspectives of relevance to nursing, *Journal of advanced nursing*, 30, 1388-1395
- McCance T V, McKenna HP, Boore JRP (2001) Exploring caring using narrative methodology: an analysis of the approach, *Journal of advanced nursing*, 33, 350-256

- McCance T V (2003) Caring in nursing practice: the development of a conceptual framework. *Research and Theory for nursing practice: An International journal*, 17, (2), 101-116
- McCarthy J (2006) A pluralist view of nursing ethics, *Nursing Philosophy*, 7, 3, 157-164
- McCormack B (2001) *Negotiating partnerships with older people: A person centered approach*, Ashgate Press, Aldershot.
- McCormack B(2003) A conceptual framework for person centered practice with older people *International journal of nursing practice* 9, 202-209
- McCormack B (2004) Person Centeredness in gerontological nursing: an overview of the literature, *International Journal of Older People Nursing (in association with the Journal of Clinical Nursing)*, 13, (3), 31-8.
- McCormack B , McCance T V (2006) Development of a framework for person centered nursing *Nursing Theory and concept development or analysis*, 472-479
- McCormack B, McCance T (2010) *Person- centered nursing*, Wiley-Blackwell , London.
- McCormack B, McCance (2017) *Person centered practice in nursing and healthcare , theory and practice*, 2nd edition, Wiley Blackwell , London.
- McCready JS, (2010) Jamesian Pragmatism: a framework for working towards unified diversity in nursing knowledge development, *Nursing Philosophy*, 11, 191-203.
- McMurray J. (1995) *The self as agent: The form of the personal*, Faber and Faber, London
- Mc Neil DG (1998, December 28) Neighbors kills and HIV positive AIDS activist in South Africa. *New York Times*, section A p5
- Mead N, Bower P, Hann M (2002) The impact of general practitioners patient centredness on the patients post consultation satisfaction and enablement *Social services and medicine*, 55, 283-299
- Meleis AJ (1996) Culturally competent scholarship substance and rigor, *Advances in Nursing science*, 19, 1-16.
- Miars R (2002) Existential authenticity: A foundational value for counseling, *Counseling and values*, 46, (3), 218- 225
- Miles A, Asbridge J (2013) Contextualising science in the aftermath of the evidence based era: on the need for person centered healthcare, *European journal for person centered healthcare*, 285-87
- Miles A, Asbridge J (2014) Modern healthcare a technical giant, yet an ethical child? *European journal for person centered healthcare*, 135-139
- Miles A, Asbridge J, Caballero J (2015) Towards a person centered medical education: Challenges and imperatives , *Education Medica*, 24-33

Miles A, Mexxicij JE (2011) The care of the patient and soul of the clinic : Person centered medicine as an emergent model of modern medical practice , *International Journal for person centered healthcare* 2, 16-21

Miller D (1995) Stress and burnout amongst health care staff working with people affected by HIV *British Journal of Guidance and counseling* 23,(1),19-31

Mimiaga MJ, Goldhammer H , Belanoff C, Tetu AM, mayer KH (2007) Men who have sex with men: perceptions about sexual risk , HIV and sexually transmitted disease testing and provider communication *Sex Transm Dis*, 34, 113-9

Molassiotis A, Lopez- Nahas V, Chung WY, Lam SW (2003) A pilot study of the effects of a behavioural intervention on treatment adherence in HIV–infected patients. *AIDS care*, 15, 135-135

Morgan D (2007). "Paradigms lost and pragmatism regained Methodological implications of combining qualitative and quantitative methods "
Journal of mixed methods research 1(1): 48-76

Morgan, S. and Yoder, L.H., 2012. A concept analysis of person-centered care. *Journal of Holistic Nursing*, 30(1), pp.6-15.

Muetzel PA (1988) 'Therapeutic nursing' in Pearson A (ed) *Primary nursing in the Burford and Oxford nursing development units*, Beckenham. Croom Helm

Murphy K, Atkins S (1994) Reflections with a practice–led curriculum, In Palmer AM, Burns S, Bulman C (eds) *Reflecting practice in nursing. The growth of the professional practitioner*, Blackwell scientific publications, Oxford, 10-19

Myeroff M (1971) *On caring*, New York: Haper & Row.

Newman M, Obermeyer A (2013) Experiences of stigma, discrimination, care and support amongst people living with HIV: A four country study', *AIDS and Behaviour*, 17, (5), 1796-1908

Newton V (2010) Teach students compasion by being an excellent role model , *Nursing practice*, 106, (39), 10

Neuman M, Makhouf Obermyer C (2013) Experiences of stigma, discrimination , care and support among people living with HIV: A four country study, *AIDS and Behaviour*, 17, 5, 1796 -1808

Nicols JS, Dosser I (2016) Understaining reflective practice, *Nursing Standard*, 4,30, 36, 34-42

Nightingale F (1969) *Notes on nursing: What it is and what it is not*. Dove New York (first published 1860)

Nolan M (2001) Successful ageing: keeping the 'person' in person centered care, *British Journal of Nursing*, 10, 450-454

Nursing and Midwifery council (NMC) (2010) *Standards for preregistration nursing education*, London, NMC

Nussabaun M (2001) *Upheavels of thought, the intelligence of emotions*, Cambridge Univeristy Press, Cambridge

O'Gara, P.E. and Fairhurst, W., 2004. Therapeutic communication part 1: general approaches that enhance the quality of the consultation. *Accident and emergency nursing*, 12(3), pp.166-172.

Ogden J, Bavalia K, Bull M, Frankum S, Goldie C, Gosslau M, Jones A, kumar S , Vasant K (2004) ' I want more time with my doctor': a quantative study of time and the consulatation *Fam Pract*, 21, 479-83

Paley J (1997) Husserl, phenomenology and nursing *Journal of advanced nursing*,26, 180-6.

Parker R, Aggleton P (2003) HIV and AIDS related stigma and discrimination: a conceptual framework and implication of action. *Social Sci med* 57 , 13-24

Packer T, (2003) Turning rhetoric into reality: person-centered approaches for community mental health nursing. *In community mental health nursing and dementia care*, Eds Keady J, Clarke C, Adams T , Open university press, 104-119.

Peplau HE (1952) *Interpersonal relations in nursing: A conceptual frame of reference for psychodynamic nursing*, GP Putman, New York

Peplau HE (1992) Interpersonal relations: A theoretical framework for application in nursing practice *Nursing Science Quarterly*, 5 13-18.

Peplau HE (1997) Peplau's theory of interpersonal relations. *Nursing Science Quarterly*, 10 (4), 162-167

Petrak J, Miller D (2002). Psychological management in HIV infection. In: Miller D, Green J (Eds). *The Psychology of Sexual Health*. Blackwell Science, Oxford.

Pollock LC(1991) Qualitative analysis. In Cormack, DFS (ed) *The research process in nursing* . Blackwell scientific publications ltd, London.

Power R, Tate HL, McGill SM (2003). A qualitative study of the psychosocial implications of lipodystrophy syndrome on HIV positive individuals. *Sexually Transmitted Infections*, 79, 137–141.

Radwin L (2000) Oncology patients' perspective of quality nursing care, *Research in Nursing and Health*, 23, 179-190

Rawlinson JW (1990) Self-awareness: conceptual influences, contribution to nursing and approaches to attainment, *Nurse Education Today*, 10, (2), 111-117

Reidpath DD, Chan KY, Gifford SM, Allotey P (2005) 'He hath the French pox' stigma , social value and social exclusion *Social Health illness* 27 (4) 468-89

Richardson L (1993) Poetic, dramatics, and transgressive validity, The case of the skipped line, *Sociological Quarterly*, 33,(4),695-710

Richardson L (1994) Writing: A method of inquiry In Denzin N K, Lincoln, Y S (eds) *Handbook of qualitative research* (pp 516-529) Thousand Oaks CA Sage.

Richardson L (1994) Nine poems: Marriage and the family, *Journal of contemporary ethnography*, 25, 3-14

Richardson L (1997) Skirting a pleated text: De-disciplining on academic life. *Quarterly Inquiry*, 3 295-304

Richardson L (2002) *Using N6 in qualitative research*, Doncaster, Victoria, Australia, QSR International PTY, Ltd.

Robson F (2002) 'Yes ! – A chance to tell my side of the story': A case Study of a male partner of a women undergoing termination of pregnancy For foetal abnormalities *Journal of Health Psychology* 7 (2) 183- 193

Rodgers BL, Knafk KA (2000) Introductions to concept development in nursing, in Rodgers BL, Knafk KA (ed) *Concept development in nursing , foundation techniques and applications* (2 ed), WB Saunders , Philadelphia , PA

Rodgers C (1980) *A way of being*, Houghton Mifflin company, New York.

Rodgers WR (1984) Person centered administration in higher education, In Levant RF, Scilien JM (eds) *Client centered therapy and person centered approach*, Praeger, New York

Rose JF (1990) Psychological health of women: A phenomenological study of womens inner strength, *Advances in nursing science* , 12, (2), 56-70

Ross M, Seeger V (1985) Short communication determinants of reported burnout in helathcare professionals associated with care of patients with AIDS, *AIDS*, 2, 395-397

Rowarth R (2011) *An interpretative phenomenological analysis of therapists working with clients who have fibromyalgia* Kindle books

Rungapadiachy DM (1999) *Interpersonal communication and psychology for health care professionals*, Butterworth- Helmemann, Oxford.

Samji H, Cescon A, Hogg RS, et al (2013) Closing the gap increases in life expectancy among treated HIV positive individuals in the United States and Canada *Plos one* , 8, e81355

Satre JP (2007) *Existentialism and humanism*, Methuen publishing ltd, London

Schon DA (1987) *Educating the reflexive practitioner*, Jossey-Bass inc, California

Schneider J, Kaplan SH, Greenfield S, Li W, Wilson IB (2004) Better physician – patient relationships are associated with higher reported adherence to antiretroviral therapy in patients with HIV infection *J Gen Intern Med*, 19, 1096-103

Segupta S, Bank S, Jonas D , Miles MS, Smith GC (2011) HIV intervention to reduce HIV/AIDS stigma a systematic review *AIDS Behaviour* 15, (6), 1075-87

Severinsson E I (2001) Conformation, meaning and self awareness as core concepts of the nursing supervision model, *Nursing Ethics*, 8,(1),36-44

- Steiner G (1989) *Fontana modern masters: Heidegger*. Fontana Press. London.
- Shilts R, (1987) *And the band played on: Politics, people and the AIDS epidemic*, New York, St Martin's Press
- Silverman D (2013) *Doing qualitative research: A practical handbook 4th edition*, Sage Publications Ltd, England
- Singh N, Squier C, Siverk C (1996) Determinants of compliance with antiretroviral therapy in patients with human immunodeficiency virus: Prospective assessment with implications for enhancing compliance. *AIDS Care*, 8, 261-269
- Slater L (2006) Person –Centredness: A concept analysis , *Contemporary Nurse*, 23, 135-144
- Smith J A (1996) Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology *Psychological & Health*, 11, 261-271
- Smith JA (2004) Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology, *Qualitative Research in Psychology* 1, 39-54
- Smith JA (2007) Hermeneutics, human sciences and health: linking theory and practice *International Journal of Qualitative studies on health and well-being* , 2, 3-11
- Smith JA (2010) Interpretative phenomenological analysis – A reply to Amedeo Giorgi, *Existential Analysis*, 21, (2), 186-192
- Smith JA (2011) Exploring the contribution of interpretative phenomenological analysis, *Health psychology review* 5, (1), 9-27
- Smith JA, Osborn M (2008). *Interpretative phenomonolical analysis-qualitative psychology. A practical guide to research methods* London, Routledge
- Smith J A, Flowers P, Larkin, M (2009) *Interpretative Phenomenological Analysis: Theory, method, research*. London: Sage.
- Smith JA (2007) Hermeneutics, human science and health: Linking theory and practice *International Journal of Qualitative studies on Health and Well being* 2, 3-11.
- Smythe E, Ironside P, Sims S, Swenson M, Spence D (2005) Doing Heideggerian hermeneutics research: A discussion paper *International Journal of nursing studies* 45, 1389-1397
- Sontag S (1998) *AIDS as its metaphors*, New York, Vintage.
- Sowell, RL, Lowenstein A , Moneyham L, Demi A, Mizuno Y, Seats B (1997) Resources , stigma , and patterns of disclosure in rural women with HIV infection .*Public Health Nursing*, 14, 302-312
- Sowell RL, Phillips KD (2008) Men soliciting men on the internet: New technology, old risk (abstract) paper presented at the *Twenty fifth annual conference of the association of nurses in AIDS Tucson :Association of nurses in AIDS care*.

Sowell, R.L. and Phillips, K.D., 2010. Understanding and responding to HIV/AIDS stigma and disclosure: An international challenge for mental health nurses. *Issues in mental health nursing*, 31(6), pp.394-402

Starr S (2008) Authenticity: A concept analysis, *Nursing forum* 43, (2), 55-62.

Sullivan A M (2000) The necessity of 'art' Three found poems from John Dewey's art as experience *Qualitative studies in education* 13, (3), 325-327

Tashakkori A, Teedlie C (1998) *Mixed methodology: combining qualitative and quantitative approaches*, Sage, London.

Titchen A (2000) *Professional craft knowledge in patient centered nursing and the facilitation of its development*, Doctoral thesis, University of Oxford, Ashdale Press, Oxford.

Titchen A (2001) Skilled companionship in professional practice. *In Practice knowledge and expertise in health professionals*. Eds Higgs J, Titchen A , Butterworth Heinemann, Oxford, 69-79

Thompson, M (2005) The way of authenticity and the quest for personal integrity, *European Journal of psychotherapy, counseling and health* , 7 (3),143-157.

Thompson M, Pascal J (2012) Developing critically reflective practice, *Reflective practice*, 13, (21), 311-325

Thompson MA, Aberg JA, Hoy JF, Telenti A, Benson C et al (2012) Antiretroviral treatment of adults HIV infection: 2012 recommendations of the International Antiviral Society of adult HIV infection: 2012 recommendations of the International Antiviral Society – USA panel *JAMA* 308, 387-402.

Tran BX, Ohinmaa A, Nguyen LT (2012) Quality of life profile and psychometric properties of the EQ -5D-5L in HIV/AIDS patients ,*Health Qual life outcomes*, 10, 132

Turner M, Payne S, O'Brien T (2011) Mandatory communication skills training for palliative care staff: Does one size fit all? *European Journal of oncology*, 15, (5), 398-403

Valimaki, M, Suominen,T, Peate, I (1998) Attitudes of professionals, students and the general public to HIV/AIDS and people living with HIV/AIDS: a review of the research, *Journal of Advanced Nursing* 27(4), 752-759

Urguhart C (2012) *Grounded theory for qualitative research: A practical guide*, Sage Publications LTD, London.

Vance D (2006) Self related emotional health in adults with and without HIV 1, *Psychological reports*, 98, 106-08

Vander Cingel C (2014) 'Compassion and professional care; exploring the domains, *Nursing Philosophy*, 124-136

Verhoeven V, Bovijn K, Helder A, Peremans L, Hermann I, Van Royen P, Denekens J , Avonts D (2003) Discussing STIs: doctors are from Mars, patients from Venus *Fam Pract*, 20, 11-5

- Visintini E, Campanini A, Fossati M, Bagnato L, Novella, C Maffei (1986) psychological stress in nurse relationships with HIV infected patients: The risk of burnout syndrome *AIDS care: psychological and social medical aspects of AIDS/HIV* 8, (2), 183-194
- Vydelingam V (2000) Asian patients experience of acute care in English hospitals: a phenomenological study, *Journal of Advanced Nursing*, 32, 100-7
- Wall C, Glenn S, Mitchinson S, Poole H (2004) Using reflective diary to develop bracketing skills during a phenomenological investigation, *Nurse Researcher* 11, 4, 20-29
- Watson J, (1985) *Nursing Human Science and Human care: A theory of nursing*. Appleton century crofts, New York.
- Webb A , Norton M (2004) Clinical assessment of symptom-focused health-related quality of life in HIV/AIDS *J Assoc Nurses AIDS care*, 15, 67-78; 79-81
- Wibberley C, (1994) The case for interactive interviewing *Nurse Researcher* 1 (3) 57-63
- Williams J, Stickley T (2010) Empathy and nurse education, *Nurse Education Today*, 32, 250-254
- Willig C, (2008) *Introducing qualitative research in psychology: Adventures in theory and method* (2 ed) Maidenhead: Open University Press.
- Williams A, (1997) Antiretroviral therapy: Factors associated with adherence. *Journal of the Association of Nurses in AIDS Care*, 8, 18-23
- Williams J, Stickley T (2010) Empathy and nurse education, *Nurse Education Today*, 30 752-755
- Witt Sherman D, Ouellette SC, (1999) Moving beyond fear: lessons learned through the literature regarding care providers and the care of people with HIV/AIDS. *Nursing Clinics of North America*, 34, (1), 1-48
- White SJ (1997) Empathy: a literature review and concept analysis, *Journal of clinical nursing*, 6, 253-257
- White M (2004) *Narrative practice and exotic lives. Resurrecting diversity in everyday life*. Adelaide ,Australia: Dulwich Centre Publications
- White M (2007) *Maps of narrative practice*, New York, NY, W.W Norton
- Wolcott H (2009) *Writing up qualitative research (3rd edition)* Thousand Oaks, CA: Sage
- World health organization (WHO) (2000) *Nurses and Midwives for health: A WHO strategy for nursing and midwifery education*. Copenhagen, WHO Regional Office for Europe.
- Yardley L (2000) Dilemmas in qualitative health research, *Psychology and health* 15 215-228

Appendix One: The Participant Information Sheet

Version 3 18.03.13

PARTICIPANT INFORMATION SHEET

Study Title: An analysis of how nurses communicate with people living with HIV – How do nurses elicit patients concerns?

Invitation to participate

I would like to invite you to take part in the following research study. Before you make a decision as to whether you wish to take part, it is important that you understand why the research is being carried out and what it would involve from you. Please take your time to read the following information carefully. You can talk to other people about the study if you feel it will help you decide whether to take part.

What is the study about?

The purpose of the study is to explore how HIV nurses elicit their patients concerns and deal with challenging communication situations. I would like to explore the nurse's experience of dealing with distressed patients and highlight what skills are used or thought to be effective within practice.

Why is it being done? What good might come of it?

The purpose of this study is to explore the belief that nurses hold about their communication skills and the impact these skills have within clinical practice when eliciting patients' concerns. The study will look at how nurses establish patients concerns and how once these concerns have been established, how they go on to explore these concerns with patients. HIV is a very unpredictable and variable disease, ranging in onset, symptoms, severity and course. Every nurse who deals with HIV

positive patients will have their own unique story to tell and these reflections will be invaluable in developing our knowledge of this area. It is hoped that the findings of this research will contribute to a greater understanding of the nurse-patient relationship and help to understand themes, models and philosophies that are used within HIV nursing in order to provide holistic patient-centred care.

Who can get involved?

Any qualified General Nurse and Mental Health Nurse who work with HIV positive patients can choose to take part. Due to study time constraints not everyone who opts in will be asked to take part. Every person who completes the confirmation slip and returns it back via email will be contacted to let them know, either way.

What will I be asked to do?

If you decide to take part you will be contacted to arrange a time to meet. I would like to talk to you about your experience of eliciting HIV positive patients concerns and how you manage these concerns once they have been expressed. Interviews will last between 45-90 minutes but their exact length of time will depend upon how much you want to tell me. The interview will take place at a mutually convenient venue. The interview will be tape-recorded so that I know exactly what has been said. You will also have the opportunity to write down any reflections you might have after the interview and send them to me.

Do I have to take part?

Participation in this study is voluntary. Prior to the interview you can withdraw at any point. After the interview, you will have until the end of December 2013 to withdraw your interview. Withdrawal will not affect future eligibility to enter research studies.

What will happen to my data? Will it be kept confidential?

At the beginning of the interview confidentiality will be discussed. You will be made aware that should you disclose anything that is indicative of significant risk either to you or others, then I have a obligation to disclose information to the appropriate person. Also, if you disclose any information that highlights unsafe practice, as an NMC registrant I will

have a duty to report the incident/s. If either/both scenarios should occur I would discuss this with you first and explain what I intend to do.

After the interview, I will listen to the tape and write down exactly what you have said. This will not be shared with anybody. I will, however, make sure that any details which could potentially identify who you are are removed and that your name is changed. You will also be sent a paper copy of the interview so you can check the content accurately reflects what we spoke about.

You can choose whom you want to tell about taking part in the research, however, I will not tell anyone. All information (tapes, transcripts and contact details) will be kept in a locked cabinet at North Manchester NHS Healthcare Trust. Information will be stored on a password protected device and accessed on a computer which has a robust firewall. After the interview has been transcribed the tape will be destroyed. All paperwork will be stored securely for a further ten years then destroyed. This is in accordance with the Data Protection Act (1998).

Aside from me the only other people who will have access to this cabinet will be my supervisors and they will only have access to the information once it has been made anonymous.

What will happen at the end of the study?

After I have completed the analysis, I may ask to meet with you or send you a copy of the main findings for you to comment on. At the very end of the study you will receive a letter summarising the study and its key findings.

Within the letter summary I will also direct you to where you could access a copy of the full report should you wish to read it. It is possible that the results of this study may be published within a journal or presented at conferences. Should this be the case all personal information will have already been removed and you will not be identifiable in anyway.

What might not be so good about taking part?

It is possible that you might find aspects of the interview distressing as you are asked to recall and explore situations that you have been involved in with patients where they have been distressed. You may disclose something that you have not discussed before or something non-routine. If you become distressed during the interview I will offer you immediate informal support as the researcher. If it is felt that you need more support as a result of what has been discussed, then appropriate services will be highlighted and a self-referral to this service encouraged.

How can I get involved?

If you are interested in taking part then please complete the confirmation slip. You can return the slip back to me or contact me via the email address at the bottom of the slip. If you would like to find out more please contact my self via the email address provided. If you have any concerns/complaints/ queries about the research you could also contact my supervisor Dr Kirsten Jack 0161 247 2405

-----**Confirmation slip**

PLEASE ONLY COMPLETE THIS SECTION IF YOU ARE INTERESTED IN TAKING PART IN THIS STUDY

Name:

Email Address:

How would you like me to contact you? (Email/telephone)

When is the best time to contact you?

Appendix Two: Interview Schedule

Interviewing schedule version 3

1. **Can you tell me what led you to work as a HIV nurse?**
 - **Exploratory questions**
 - Do you think your reasons for coming into HIV nursing has an influence on how you establish your patients' concerns?
2. **Can you tell me about a patient situation you will never forget?**
 - **Exploratory questions**
 - Can you tell me how you managed to establish your patients' concerns in this situation?
 - Can you describe to me in as much detail as possible what skills you used in this situation when trying to establish your patients' concerns?
 - How do you think this experience has helped you when establishing your patients' concerns?
3. **Can you tell me about a patient situation where you encountered strong emotions with a patient? In particular I am interested in hearing experiences where patients have been distressed.**
 - **Exploratory questions**
 - Can you tell me how you managed to establish your patients' concerns in this situation?
 - Can you describe to me in as much detail as possible what skills you used in this situation when trying to establish your patients' concerns?
 - How do you think this experience has helped you when establishing your patients concerns?
4. **Can you give me an example of how you would respond to the concerns your patient has expressed?**
 - **Exploratory questions**
 - Can you give me another example ?
 - What skills do you think you used in the situation you described?
 - What do you think worked well?
 - What do you think didn't work so well?
5. **Can you tell me how you learned how to elicit/respond to concerns in this way – what knowledge did you draw on and how did you come to acquire such knowledge?**
 - **Exploratory questions**
 - Can you tell me more about this?
6. **Can you tell me what has informed your current understanding of how best to elicit and respond to patient concerns (experiences may be professional or personal)**
 - **Exploratory questions**
 - Can you give me another example?
 - Can you expand on this?
7. **Alongside your experience as working as a nurse have there been any other experiences that you consider to have been important in shaping how you elicit and respond to patient concerns?**

- **Exploratory questions**
 - Can you tell me more?
8. **Are the skills that you have described something that you have always had or something that you feel has developed with time and during your practice?**
- **Exploratory questions**
 - If these skills are something that you consider to have always been there are you able to tell me about how you learned these?
 - What experiences were important in developing your knowledge of these and who would know this about you?
9. ***Has working with HIV patients affected what you now consider important when discussing concerns with patients?***
- **Exploratory questions**
 - Why do you think that is?
 - I would be interested to hear what effects your experiences of working with PLWHIV has had on your ability to explore patients' concerns?
10. ***Is there anything else that you would like to talk to me about in relation to this topic?***

Prompts

Can you tell me more about that?

I would be interested in hearing more about...

When you mentioned ... Can you explain to me more about this?

Could you give me an example?

Could you explain that further?

What caused you to feel this way?

Appendix Three: An example of a participants' transcript

Emergent themes	Transcript P1 Pseudo name: Harry Male 30-39 Length of HIV nursing experience:5 years	Exploratory coding
	<p>Me: Thank you for agreeing to be interviewed today Not at all Me: I'm just going to ask you a few questions so feel free to answer them as openly as you want and it will last as long as you want it to Right Me: Can I just start by asking - can you tell me what led you to work as a HIV nurse? Initially when I was at university, before I did my nurse training I went to South Africa and did some volunteer working at school into HIV awareness and when I cam back I wanted to carry on so that I worked with a charity that worked with people with HIV in Manchester. I did some training and I've also wanted to work with HIV and I knew that in North Manchester, where I work now there was a big field, a big area of HIV in the Regional Centre for HIV, so I kind of made it an effort to get a job here as a staff nurse and carried on doing my volunteer work, and initially worked with people on a ward setting. I think the reason I wanted to work with people with HIV is, for me, was that it was a misunderstood area in a lot of ways and I felt I wanted to learn more myself about it by kind of working in it and also hopefully then teach others about HIV. When I was in South Africa I was quite shocked by the way people were treated and by how HIV was thought about over there. Working back over here and brought some knowledge about it I actually found there were some similar beliefs with people over here, so worldwide there is still a stigma attached to it, I suppose, and I felt that I wanted to bring that down a little bit with in terms of my job, and in terms of outsider work as well, I suppose. Me: Do you think your reasons for coming into HIV nursing have influenced your</p>	

ability to establish patients concerns?

The reasons? Sorry can you repeat the question

Me: Sorry, do you think your reasons into HIV nursing have an influence on how you establish patients concerns?

Yes I think so, establishing the reasons behind coming in and wanting to break down that stigma is then you're aware of what patients might be concerned of in terms of their healthcare, or if there is anything we can do outside work and what's bothering them at the moment, I suppose. You bear in mind that they are going through. They are coping with a lot on top of their health really, or being in hospital or coming to a clinic appointment. They've got family issues, they've got relationship issues, they've got all sorts behind them, and I think having awareness of coming into HIV I wanted to try and help people around that, so when you're trying to help people with their concerns, because they are so multi factored and there's so many of them, you're aware it is a lot to cover and you've got lots of different things to try and help people sort out and try and get them to tell you.....I suppose. Does that make sense ?

Me: Can you tell me though about a patient situation that you'll never forget?

(Ooh, umm, (laughs)) yes (umm) I had a patient when I was working on the wards, he was a young gay man who came in who was very unwell, he had a partner both hadn't been tested for HIV when he came in. He was unwell and (umm) we did HIV test on him which we do as routine on the wards, and it came back positive, and I remember having a conversation with him afterwards and he basically said that he'd kind of buried his head in the sand for a number of years, and he and his partner had never really spoken about it and just kind of trundled along and he'd become generally unwell, but never thought to have a test. His partner was really supportive and his Mum came in and was really supportive and he had PCP up in high care and had become really unwell and confused, and I think I was on quite a lot that week when he was in and he ended up going into ITU and he died and he was only (well I was probably only about 23, 24 or 25 at the time) and he was a bit older

than me, probably as old as I am now, about 31 and I remember thinking, I don't know, it was very difficult because he was so young and it shouldn't have happened and he knew that as well and his partner knew that. I mean it always sticks with me, so I remember he (umm) transferred into ITU and he was quite out of it and was intubated and I went to visit his Mum on ITU when he wasn't well and he ended up dying and his partner came to visit him all the time and hopefully I provided them some support, but I'll never forget him and his partner because they were young gay men, like me I suppose, and I just thought, you know, this shouldn't happen, but it did happen and hopefully I was able to provide some support for him and his partner, you know, after his death ultimately I suppose, but (umm, laughs) I remember actually, I bumped into his partner a couple of weeks afterwards when I was out in town (laughs) as you often do, as I often have done in the past, and (umm) he came over to me and kind of said 'thank you for everything that you did' and that kind of sticks with me as well, and you know, but I always remember it, because I think why didn't you go earlier? Why didn't get a test? But for whatever reason, that was his choice and then you know, he ended up there he was and we ended up nursing him and hopefully he got some peace eventually, yeah.

Me: I understand that was quite a frustrating time for you?

Yeah it was really. It was frustrating I think in terms of obviously his situation. That was his situation and it wasn't mine to have any control over it, (umm) and it really kind of highlights to me I suppose, about you know, you can't assume that everyone is going to get tested just because they're gay or you know, because they're in a high risk group, you know, and obviously we do focus on people who aren't in the demographic that you would assume, but actually sometimes everyone needs a reminder, you know and I think that was frustrating and also what I found is that he was very young and he became confused, he was hypoxic and to go from someone being admitted and you know what it's like with PCP, to be generally quite well and on i.v. Septrin and

you think everything is going well, and then two days later he's gets the worst of it. So that was frustrating, because he was well and you kind of do think, and I remember thinking at the time 'oh he'll be OK actually' and yeah his CD4 count is really low really low and he's probably going you know, get some trouble, but he'll be fine and then I remember I came in and he was unwell and he did kind of go off overnight and yeah it was frustrating and it was upsetting as well because he was someone who was young and kind of well, and you know, actually lovely to look after as well, to kind of become confused and obviously for his partner as well it was very difficult for. Probably more difficult for his partner than it was for me, but to kind of see someone change, I suppose because he was very close of course.

Me: How do you think you were able to manage the patient concerns in that situation?

He was very scared, and he was very scared about little things i.e his drip not going through and that kind of stuff and also obviously the bigger picture scared about what was going to happen to him. And I hope that, I think I was able to reassure him just by giving him information, telling him exactly what was happening because you know, asking him what he was concerned and what he was bothered about. If it was something as simple as kind of you know, 'do you want some water' as I could see he was in a difficult place, or 'do you want to talk about exactly what is going on?' But I think at the time, for him, it was more, as he was acutely unwell, it was more of a bit by bit, what's the next plan, what's going to happen you know, what's going to happen, what meds am I on, you know what drug is this, is it going to make me feel better? They were his immediate concerns, but I think, obviously then you give him the information and you just spend time and get the information yourself if you don't know and kind of go through that. To be honest with you, those kinds of concerns I find even in well patients, are a bit easier to manage. When I became specialist nurse in HIV I always remember saying to people, when you're on the ward you're dealing

with the immediate things like getting someone's fluids up, then you see someone in clinic whose very well but has time to talk to you about their concerns and I remember thinking, oooh this is difficult, because you know, not that I would any run away from anything on the ward, but you've got easier concerns if your dealing with immediate concerns of the patient as well and their concerns are like he said, well what are these meds – oh I can deal with that that's easy, but then you've got somebody in a different situation, who is an outpatient, just come in who says I've got my diagnosis and I don't know what to do and then that's a different kind of way of dealing with it I suppose.

Me: Do you think in that situation you would use a different set of skills?

Yeah, well I had to learn a different set of skills. I hope that hopefully I already had a few, but I did find it quite difficult that transition and I think definitely well analytical skills I use a lot, but the kind of active listening and the being aware of using your time more appropriately as well, I think, not more appropriately, but in a different way. So I kind of appreciated that you can spend half an hour or even more with somebody to get out what really is bothering them, or what their concern is, as opposed to you know, them having an immediate problem that you can give a direct answer to. Sometimes it takes a while to get out exactly what their concern is. It might not even be in that first meeting that you have, it was also about relationships and using the skills of 'OK I'm here, this is what I do. Use me for what you want, you know, you don't have to come and see me if you don't want to. You can if you want to and we can talk about this or we don't have to', but kind of getting to know you and trust the Trust I think which happens in all aspects of nursing doesn't it, but I think when you're in that one to one specialist level, I suppose, it carries a bit more (umm) I find it difficult to build up sometimes i think really. Yeah..

Me: You mentioned that you have developed some more skills. I'm just interested in where you may have developed those skills from?

Developed then from? I think probably from my

nursing experience in general. I think there are a lot of transferrable skills and obviously, you know, sometimes when you are acutely on the ward you are used to doing those like listening skills, although you kind of, but you are, so I think I've developed them as I've gone along. I think outside of work, with the charity that I worked for, working with people with HIV for quite a while in that sense has helped me develop those skills, I think.

Me: Can you tell me about a patient situation when you encountered strong emotions with a patient? Think about a patient who was really distressed.

Yeah (umm) so I had a young, well a chap in Liverpool when I worked as a specialist nurse, who was an African chap who (umm) basically came in to see us, I can't remember his background. He didn't present very unwell, he was an inpatient but he was referred from somewhere else, I think London as an outpatient. He had a very low CD4 count, very non-adherent, resistant virus, been on different medications, been back and forth home a few times and been given different medicines. And, I'm trying to remember the story in my head now, he worked in a university in his home country and he came over here. He didn't have any access to public funds, lost his job and lost his relationship with his wife because of his HIV diagnosis and they had a child as well. (erm) He didn't have that much contact with them back at home as they really didn't want anything to do with him. So all these things kind of built up. I saw him quite a few times and the doctors as they do said we'll put you on these medications and you'll be fine and you know, but the poor man came to us with his adherence and there were other things going on, like places to live. He was very, I think he was very sad about his whole situation, understandably, because he'd been through quite a lot and I remember being kind of upset in general, and he'd had bad experiences of taking medications in the past with nausea, diarrhoea, and he was put on similar medications he'd been on before. He was a very smart guy, very clued up and he didn't want to get back on these and I remember him being kind of very aware of the

situation and you know, it was difficult because at first, I thought I was going to solve all his problems and you know told him the was going to be OK and then I think our relationship built up, which I tried to do in terms of trust and in terms of kind of him coming in to have chats, if that's all he wanted to do. Hopefully that got better as time went on and he was able to not even, I think maybe it was frustrating for me because initially I was thinking a bit more of a point of view of kind of you know, if you took your medications you'll feel better, but then you gradually got to know well actually you know you are making decisions, we're giving you information, drip feeding you information, you're asking for information eventually and the relationship built up eventually and I think I changed my approach to him a little bit I think, hopefully. I learnt as I went along as I sometimes say. I thought I was quite new to it and I felt a little bit out of my depth to be honest, because he was very sad and quite complicated and I thought maybe at first, I'd kind of pushed him a little bit and then hopefully I learnt and cooled off a little bit. Does that make sense?

Me: It does make sense. I'm just interested because you describe quite nicely how you sort of changed your approach?

Changed my approach?

Me: How do you feel that happened?

I think it was probably out of the results I saw. Not that I ever went in you know, and said, 'you will take your medications' I wouldn't do that, but I think I saw the results with him. You don't know somebody and you think, right this strategy will work and when you don't see someone maybe improving, or you don't see someone maybe you know, it's so difficult to measure outcomes in HIV because you know, it doesn't mean that if someone takes their medications that you have done the job, you know what I mean, it's not what it means. You can still do your job amazingly even when people don't take their medicines that's part of the job, but initially I was mainly thinking about it from one point of view, seeing that he really wasn't improving. He didn't want to adhere and then because of the

outcomes, not the outcomes, do you know what I'm trying to say that if I was looking at how he was doing and I changed my strategy around that. Does that make sense? I suppose that's a good one, you're looking at it but outcomes are so difficult, as I've said in HIV that you're thinking 'how am I measuring that my strategy is helping this patient? Am I getting the concerns out? Am I managing to kind of help them? You know what different way could I help them and I think just through conversation with him about his family and about back at home, and we talked about that for a while, forget about the medications let's just talk about that a little bit. He didn't have much in his life in Liverpool and so I tried to get out of him little bits that he did and told me about some of his friends that he had and that kind of thing and you know your strategy moves then from being medically focused to being kind of building a relationship I suppose.

Me: Do you think that was important to build?

Yes definitely. Yes definitely for whatever reasons I LEFT Liverpool and I do think about him sometimes about how he's doing and I think it would have been ideal to have built up that relationship a little bit more.

Me: Do you think your experiences of dealing with that patient have had an impact on how you would establish concerns in future?

Definitely, yes without a doubt. I think you know, as you know, it was a new job to me doing specialist nursing and he was one of my first patients and it was very complicated. I've got to be honest with myself, initially I don't think I dealt with it that well, but hopefully I learnt from it and hopefully I did change a little bit and hopefully you know, maybe helped him a little bit. From learning from him I obviously changed myself and if I was in a similar situation then I hopefully would be able to deal with things differently, but you never know do you so.

Me: Can you give me an example of how you would respond to a concern your patient had expressed?

A particular concern or in general how I would?

Me: Whichever you feel

I suppose I always try and repeat concerns back to people, so that I can make sure that I've understood them properly. (umm) I just repeat I suppose and know what their main concern is, and then I suppose it's about where that concern's come from, obviously that's the main concern that you've voiced (umm) and just believe is the important thing and just appreciate it as a concern whatever it is, is really important and acknowledging that it is a concern and make sure that you address it appropriately. You know appropriately doesn't have to mean that you go into those concerns inappropriately, it can also mean you know, that's something we can stress now, because people do come to you with things sometimes that you know I do it all the time with myself, socially with friends I suppose but you know you work something out in your head and you get it out and actually the person you speak to goes 'you know you can actually do this and think about that' and then you say yes actually I could couldn't I and actually probably feel better now and sometimes I think when people come to you with a big, big concern and you say you know what why don't you try and do this. There was patient in Liverpool, he was lovely, he was gorgeous and he was just having a bit of a tough time like he was really close to his auntie and his Mum was unwell and he asked for a chat with us and he was like, things are really getting on top of me, and we just chatted for about 5- 10 minutes and he was like, you know what I feel all right, got it off my chest. And I was like it's fine, you know, you can come to me with anything and obviously you take their concerns seriously and listen to what they have to say, but I think it's believing what people say to be able to offer support. Sorry I'm rambling on now.

Me: That's good, Good stuff. What skills do you think you used in that situation that you described?

(Umm) listening skills, obviously being compassionate, being caring, general nursing skills really I suppose, you know, making sure you believe your patient and address any concerns I suppose, empathy, advocating to people all the time because you believe in what

they say and obviously you can take those concerns on and help them in a way you see fit,. Whether that is involving anybody else or something you can deal with yourself (erm)

Me: Can you tell me how you feel you were able to establish these concerns in patients? What knowledge did you draw on and how do you feel you acquired this knowledge?

So it's learning these concerns especially when you're working in the area if you learn about HIV, you learn about you know the virus, what's behind it, you learn about medications, you are armed with information to give to people, but also I think you learn about the issues the stigma, you learn about relationships, issues on top of just the health care and so when people come to you , they feel comfortable that you know what kinds of things they are going through and that you've had experience in helping other people who have been in a similar situation and your not kind of getting well how does this relate to your HIV when they come to you and say, well I've fallen out with my partner or I've you know, cheated on my girlfriend or I've done this or whatever. Maybe they're not in a relationship at all and that can be completely different but you're that person who is hopefully clued up and you've got that skill and I think I've got that skill through different areas of work and through learning from colleagues and learning from education that I've been on and kind of getting ideas from patients as well like how have you been treated in the past, did you think you were well treated, do you think people did listen to your concerns. There often very isolated and there are different areas that they want to speak to you about, you know, they are stigmatized basically and I think it is a privilege when someone comes to you with HIV or not HIV and are comfortable around you and I think that's a skill that as HIV nurses we need to be more proud of sometimes. It's not easy and I think sometimes people think oh HIV nurses you just give them medicines and hold their hands and stuff, but actually the skill in just being with somebody and accepting them and I'm so proud of that and it's a skill that all my colleagues have, people that work on the wards, people who are

specialist nurse, just to be with people and make them feel not judged. Just to feel that if they've come to see you, it's rubbish to think that every hospital thinks that they have to come to an appointment or be an inpatient but that you can just be the one that they can be normal with. Sorry rambling again, but that's what I think that in terms of dealing with people's concerns it's about starting off with a benchmark, your bottom line that you're not judging them about HIV. You might give them advice about their lifestyle in whatever capacity, say in their drinking , using drugs or you know getting them help professionally, but the bottom-line is that you're not judging them because they have HIV.

Me: Thank you. Can you tell me about your current understanding of how best response and elicit patient concerns?

(Umm) experience. That definitely is the main thing, I guess making an effort to better your own understanding of what communication is and kind of the best way to do it. I think (coughs) I've made a conscious effort to kind of do a bit of looking for communication skills and listening skills and that kind of thing and helping people get their thoughts an feelings out I suppose really. I've done it for myself in a sense and people have taught me ways to deal with emotions or deal with concerns and get feelings brought out and I've used those skills. So I've got experience form work, experience from educating colleagues, speaking to people and getting advice and you know, again asking patients, I don't think we do it as much as we should, because sometimes it feels a little bit false to them like saying to a patient 'how do you think that consultation worked? How did I communicate?' but I suppose that's how to get the best feedback so it's really valuable if you've not done enough maybe

Me: Alongside your experience of working as a nurse have there been any other experiences that you consider have been important to what has shaped your ability to understand concerns from patients?

(Umm) so I suppose a couple of things in terms of HIV, working in the voluntary sector and kind of being aware of things in terms of healthcare.

Because a lot of the time people will potentially go to a secondary organisation with other concerns and they might not come to us. Obviously I work there and I can see that this person is bothered about this, but it's a different role and I'm aware there are bound to be differences, but I think having that awareness of that kind of care, as I think we all do, I think that is really helpful and again I think that my experience and just kind of how I deal with concerns or how I help my friends deal with concerns and that kind of thing. Does that make sense?

Me: Are the skills that you've described something that you have always had or something that you feel you have developed with time?

(Umm) I guess the latter definitely. We're always developing and like to think that we're always with someone who listens and kind of help people draw out their emotions or their feelings, gives us good ideas in terms of HIV I think I've definitely grown and this is reflected in the example I gave about the potentially difficult man that I helped in Liverpool. I definitely saw my approach change which I thought was definitely for the good. I think (coughs) gaining more –knowledge over time to elicit peoples concerns and knowing the current issues that they might be concerned about I suppose is important, Keeping up to date with research and keeping up to date with current issues in HIV. So you know someone might be concerned about transmission or prevention or something or they're negative like I'm not on treatment I should go on treatment, what do you think? If you don't know then it's like keeping up to date with that kind of stuff and again to be open to that kind of questioning to anticipate it or to answer it so that everyone should be aware to keep up to date, because in essence you are a specialist, or you work in an area that is in a different field and people are asking you for advice and so you know I suppose we owe it to them to keep up to date and be aware of those issues, I suppose. It's interesting as well so it's why I want to do it to help people I suppose. Other skills are just listening and just the non judgemental thing I mentioned and that's

something I've hoped I've always been you know but then you know you do change, but you get experience as you go along and being open to learning I suppose and to be open to change and criticism as well, and taking, you know constructive criticism and doing something with it.

Me: What experiences developed your knowledge of how best to elicit patients concerns and who would know this about you?

You want to know about my experiences (Umm) I think the difficult situations at work, you know, helped me increase my knowledge, definitely working with the colleagues I work with, specialist nurses, specialist staff on the ward, learning from them, learning from a lot of people who've got a lot of experience in the past or new people as well. (Umm) people at George House Trust definitely. My friends who are positive. I think in terms of my knowledge around HIV (umm) but I suppose...can I have the question again?

Me: What experiences have helped in your knowledge of HIV and who would know this about you?

My experiences obviously working on a ward as a specialist nurse, experiences in volunteer work and as for people who would know about me, my friends know my area of interest and they encourage and they ask questions, and they are interested and they know that you know, I try to better myself and stay updated as we all do I suppose, and my colleagues at work I think recognise that I want to help, want to improve and want (laughs) progress and gain knowledge and that sort of thing.

Me: Has working with HIV patients affected what you now consider important when discussing concerns with patients?

Yeah, definitely, going back to what I said about you know, holistic concerns, that might be medical concerns that might be related to the treatment, but might be related to something completely different. Recognising that people's concerns can be more multi faceted and that you know you could be talking about one issue and then it could lead to something else and it could

be a load of different things and the amount of issues that people do potentially do deal with takes a lot of time to get through in consideration of the time and the relationship building that will potentially be needed to elicit those concerns from people. It's not like a bam, bam, bam these are the needs and issues that I can talk about and in terms of like dealing with people with chronic illnesses as well, in any sense working with people with HIV has enabled me to look at things more realistically and people with chronic illnesses of all kinds all have the same issues as well, so I think you know, working with hepatitis C as I do now as well has given me the opportunity to kind of make sure I cover all bases I suppose, and I give people time and I think as nurses we're good at that anyway, but with HIV I think it's that appreciation of the bigger picture of kind of all the different things that people go through when they get or whether they live long term with the diagnosis or whatever stage in their journey they're at, their concerns are going to be multi faceted and changing I suppose all the time, and there is generally going to be a few more than just the one concern and hopefully you know, well there may be just one concern at times, and as I said at the start it's about listening and appreciating that and being able to deal with them appropriately and help the patient deal with them appropriately I suppose. You're a pal with patients ultimately aren't you and we like to see ourselves sometimes as helping people as problem solvers, but ultimately I think what we want to do is help patients solve their own problems and deal with their own concerns, not in a 'you can deal with it yourself' but in a 'let's give you some tools for you to be able to deal with it yourself'. So maybe that's the greatest thing you can do in terms of getting people's concerns out is for them to feel that they are able to then do something about them themselves. I do that from my own experience, we all want to go to somebody and say 'help me out', so actually that, giving them the tools to sort their own concerns is a good outcome I suppose.

Me: Is there anything else you would like to talk to me about in relation to this topic?

No it's really interesting thank you. (Laughs) I've

really liked it, it's been very cathartic and I know I've rambled on but no it's really good and it's difficult because it's the trust thing sometimes. We're so used to dealing with people with HIV but the person who's just diagnosed who doesn't really know anything about it, they're not going to be able to sit and have an open conversation with you as much as you know about HIV, and I think we're all good at remembering that, but we need to remind ourselves when we see somebody new, they're going to have questions and their questions are going to be, well probably be very, very different for everybody but you know, their concerns are going to be, yeah, things that we feel are easy to deal with but for them you know, I'm talking about people giving them their own, you know we need to deal with that, oh what does CD4 count mean, oh I can tell you that it's really easy, but we don't do that, obviously we don't, we take it very seriously and explain the ins and outs of it. Essentially what you want is then for the patient to then be able to you know, know what that is and give them the number if they want it or not worry about it if they don't want to worry about it. So it's about that time and that relationship isn't it really. So good yeah.

Me: Thank you very much.

Appendix Four: Example copies of Ethical Approval



MANCHESTER METROPOLITAN UNIVERSITY
FACULTY OF HEALTH, PSYCHOLOGY AND SOCIAL CARE

MEMORANDUM

FACULTY ACADEMIC ETHICS COMMITTEE

To: Michelle Croston

From: Prof Carol Haigh

Date: 05/04/2013

Subject: Ethics Application 1172

Title: An analysis of how nurses communicate with people living with HIV – How do nurses elicit patients' concerns?

Thank you for your application for ethical approval.

The Faculty Academic Ethics Committee review process has recommended approval of your ethics application.

We wish you every success with your project.

Prof Carol Haigh and Prof Jois Stansfield

Chair and Deputy Chair

Faculty Academic Ethics Committee



Research and Development
Trust Headquarters
North Manchester General Hospital
Delaunays Road
Crumpsall
Manchester
M8 5RB

**Dr. Christina Kenny – Deputy Medical Director /
Director of Medical and Dental Education**
T: 0161 604 5474
E: christina.kenny@pat.nhs.uk

Katie Doyle - R&D Facilitator
T: 0161 604 5233
E: katie.doyle@pat.nhs.uk

**Dr. Steve Woby – Head of Research &
Development**
T: 0161 720 2229/ 0779 1458 483
E: steve.woby@pat.nhs.uk

Kat Moklak - R&D Co-ordinator
T: 0161 922 3378
E: kat.moklak@pat.nhs.uk

Miss. Michelle Croston – Specialist Nurse Infectious Diseases
The Pennine Acute Hospitals NHS Trust
North Manchester General Hospital
Delaunays Road
Crumpsall
Manchester
M8 5RB

7th December 2012

Dear Miss. Croston

R&D reference number:	12RECNA43
Project title:	An analysis of how nurses communicate with people living with HIV in order to establish their concerns - How do HIV nurses elicit patients concerns?
Site:	N.M.G.H.

Thank you for providing the Research and Development (R&D) department with the required documentation for the above study. I am pleased to inform you that the study has been noted by the R&D department at The Pennine Acute Hospitals NHS Trust. As this study did not require approval from the National Research Ethics Services (NRES), details of the study will remain on our R&D database for 'notification only' and no further action will be taken.

I would be grateful if you could provide us with a summary of your findings upon completion of your study.

Yours sincerely

Dr. Steve Woby
Head of Research & Development

cc: Cynthia Murphy - Manager I.D Research Dept & HIV / Hepatitis Support

Version 2