

Cause for complaint? The experiences of nurse patients and nurse relatives who receive poor care: A qualitative study

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Abstract

Aim: To identify the circumstances in which it would be easier for nurses who find themselves in the role of 'patient' or 'relative' to complain when they have received or witnessed care or treatment they feel could be improved.

Design: A qualitative interview study.

Methods: Data were collected using a semi-structured interview with 12 nurse patients and nurse relatives in Scotland. All interviews were face to face, recorded, transcribed and thematically analysed using Reflexive Thematic Analysis (Braun and Clarke, 2013, 2022).

Results: Participants provided rich and often harrowing accounts of their experiences of receiving or witnessing care. The analysis produced the following themes: Insider/outsider (overarching); 1. Through the nursing lens with subthemes (i) It's all magnified, (ii) Blurred boundaries (iii) The hidden code; 2. Loss of trust; 3. See no evil, hear no evil, speak no evil; and 4. Using my insight to make a difference.

Conclusion: While their insider knowledge gave a unique insight into the experience of care and treatment, the complexity of the nurse patient's and nurse relative's insider/outsider position also made it difficult for them to complain when they received or witnessed poor care. Changes to leadership, policy, practice and education are required to make it easier for nurse patients and nurse relatives to complain so that the opportunity to learn from their rich experience is not lost.

Impact: The limited evidence available about the experience of nurses who find themselves in the role of patient or relatives of patients comes from different countries suggesting that this study is of international interest. Previously under researched, this study contributes to the existing body of evidence by looking uniquely at the experience of nurse-patients and nurse-relatives through the lens of complaints.

Declaration

I declare that the work in this thesis is my own.

Jacqueline J Macrae
27 April 2022

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CHAPTER 1. SETTING THE SCENE

1.1 Introduction

The purpose of this chapter is to introduce my thesis. I begin by setting out why I chose this subject for my research before providing an overview of the background and context for the study. The overall aim and research questions are then presented and, finally, the outline structure of this thesis, supported by a brief summary of each chapter.

This study adopts Reflexive Thematic Analysis (Braun and Clarke, 2013, 2022). To reflect the underlying philosophical stance and researchers position in the study, much of this thesis is written in the first person rather than the objective, scientific third person (Braun and Clarke, 2022). I discuss this more fully in Chapter 4.

Why this subject?

My interest in patient experience and voice first began in the early 1980s after reading a book from the course recommended reading list during my early nursing studies. That book was Barbara Robb's *Sans Everything: a case to answer* (1967). Robb's book describes the appalling ill-treatment of elderly patients in a number of psychiatric hospitals in the UK and this is discussed further in setting the background and context for this study. My interest in how we can learn from patient experience, particularly when things go wrong, has stayed with me. I developed an interest in complaints management during my time working as Patient Focus and Relations Manager in an NHS Board in Scotland, where complaints management and patient experience were a significant part of my role. Complaints can provide important insight into where there is a need for improvement (McCreddie et al., 2018). If complaints are not received, that opportunity for improvement is lost (Van Dael et al., 2020).

Defining a complaint

Complaint: *'An expression of dissatisfaction by one or more members of the public about the organisation's action or lack of action, or about the standard of service provided by or on behalf of the organisation.'*

(Scottish Government & Scottish Public Services Ombudsman, 2017)

The definition above describes a complaint as '*an expression of dissatisfaction*'. Van de Walle (2018) describes consumer satisfaction/ dissatisfaction with services as complex, taking into account expectations, experience and prior knowledge. Originally developed in consumer behaviour research, the dominant theory of satisfaction is the Expectancy-Disconfirmation Model (EDM). A meta-analysis of 17 studies, over 15 years, on the use of EDM in public sector research found that the model provided valuable insights into the quality of services and supported its use in further research (Zhang et al., 2022). The EDM Model suggests that when services exceed expectations (positive disconfirmation) then satisfaction occurs and when services fail to meet expectations (negative disconfirmation) dissatisfaction results. According to Van de Walle (2018), people that have high expectations of a service are more likely to be dissatisfied than people with low expectations.

Response to dissatisfaction

Albert O Hirschman (1970), in his seminal work, argues that there are three main responses when customers or citizens are dissatisfied with goods or services; they will either exit and go elsewhere, they will complain, or when influenced by the level of loyalty they have towards the product or organisation, they may neither exit nor voice but suffer in silence.

Exit is a limited option for many who use health services, and the literature identifies many reasons other than loyalty as to why patients are often reluctant to complain about their healthcare, including concerns that it would not make any difference, might adversely affect future treatment (Clwyd and Hart, 2013; Craigforth, 2009; Scottish Health Council, 2014), or do not want to get staff into trouble (Brüggemann, 2017). In addition, particular groups have traditionally found it difficult to complain, such as people with mental health problems (Haw et al., 2010), older people, black and minority ethnic groups, young people, people who are homeless, and those for whom English is not their first language (Craigforth, 2006, 2009).

When people do complain about the healthcare they have received, it is often at a distressing time and about a subject that can be complex, filled with medical jargon, and difficult to articulate. The complaints process can be long and protracted, further adding to the distress of patients and of staff involved (Bourne et al., 2016, 2017; McCreddie et al., 2021). McCreddie, Benwell and Gritti (2018), following the analysis of 60 complaint letters, found that complainants endeavoured not to be perceived as ungrateful or moaning. They also found that complainants worked hard

to build a case to convince the reader of the injustice and hurt caused. In a further study of complaint responses, McCreaddie, Benwell and Gritti (2021) found that many complaint responses failed to address the issues raised, were defensive and lacked a meaningful apology.

When the patient or relative is a healthcare professional

Anecdotal evidence through periodic discussion with NHS colleagues suggests there is another patient group who find it difficult to complain; those patients and relatives of patients who are also healthcare professionals, often employed by the Board in which they find themselves in the role of patient or relative. The examples of poor experience described by colleagues who did not complain varied from rudeness of staff to serious concerns about end-of-life care for their relatives.

One reason that healthcare professionals may find it difficult to complain is that they would potentially be raising concerns or complaining, not just about an outside service, but about their employer and their colleagues with whom they might have an on-going working relationship. This was illustrated by a colleague who described why she had not complained about the poor end of life care her mother had received.

'It's difficult when you are a nurse and 'on the other side'. I wanted to complain but my mum was being looked after in another ward in my unit and my line manager would not have supported me.'

I wondered what it really meant to be on 'on the other side'.

A physiotherapy colleague had a similar story. She did not complain about her outpatient appointment because she thought '*being seen as a troublemaker*' would look bad for her professionally and it might influence her future treatment. Again, I wondered; what was it about doing a healthcare job that meant it was so difficult to raise concerns as a patient? The voice of healthcare professional patients is important as, unlike lay people, they understand both clinical language and the 'NHS System'.

Anecdotal evidence, particularly that which is emotive, can be persuasive (Freling et al., 2020; Michal et al., 2021). However, relying on anecdotal evidence to change practice is problematic. For example, people tend to give undue credence to their most recent and negative experience (Irwig *et al.* 2008). While criticised for being weak evidence because of the inherent bias, anecdotal evidence such as the aforementioned examples can be useful for identifying areas for research and to support research design. (Moore & Stilgoe, 2009)

Initially, I considered including all healthcare professionals in the study, but decided to focus on nurses for three reasons. Firstly, I wanted to focus on my own profession because, as well as being my passion, I felt it would provide a clearer demarcation for the scope of my study. Secondly, 'healthcare professionals' are a heterogeneous group covering many professions and roles within the NHS. It is possible that people experience care and treatment differently depending on their occupational group. For example, while doctors may be reluctant to admit that they are ill, they may be more likely to use professional networks to influence their care and treatment (Jones, 2005) than other professional groups. Thirdly, I considered my own position within the study. In qualitative research the researcher is the instrument (Kvale and Brinkmann, 2009; dos Santos Martins *et al.*, 2020). The relationship with participants is fundamental to the quality of data collected. In part, this relates to the stance adopted by the researcher along the continuum of objective outsider or as an insider with accepted subjectivity. My positionality as a nurse researcher is an issue that is explored reflexively throughout each phase of my study.

1.2 Background and Context: A history of NHS complaints management

Setting the context for my study at the outset is important because it not only outlines the setting in which the nurse patients and nurse relatives have experienced care, but the system that they work in and are part of. To illustrate the complexity of complaints management within the NHS, and why it is so challenging for patients to complain and for the NHS to learn and improve, I go back to the inception of the NHS and consider its changing relationship with patients, and the key factors that have influenced patient voice and complaint handling.

The landscape is complex, with changes such as the internal market influencing public relationship with the NHS (consumer and stakeholder), the impact of high-profile scandal on policy, and the divergence of policy as a result of devolution. This section is presented in chronological order, firstly to aid clarity in a complicated landscape, and secondly, because while looking over the years shows a picture of positive change in complaints management, it also illustrates that there is still much to do.

High Expectations

In 1948, the government sent a leaflet to every household stating what the public could expect from their new National Health Service.

“It will provide you with all medical, dental and nursing care. Everyone – rich or poor, man, woman or child-can use it or any part of it. There are no charges, except for a few special items. There are no insurance qualifications. But it is not a “charity”. You are all paying for it, mainly as taxpayers, and it will relieve your money worries in time of illness”.

Ministry of Health (1948)

Within this first paragraph, the leaflet sets out the public’s position, not just as “consumers” of health care, but as “owners and stakeholders” with a vested interest in its success. While it is likely that there have been cases of dissatisfaction with treatment since the inception of the NHS, at a time when the medical profession dominated and patients had limited voice, there were no clear routes for people to raise concerns. In the 1960s the concept of patients as consumers with rights began to emerge in the UK, with organisations such as the Patients Association campaigning for people to be given more information about their illness, and for consent to be obtained prior to enrolling in research or used in teaching (Mold, 2012, 2015).

In the late 1960s, two seminal, high-profile scandals led to changes both in the public’s relationship with the NHS and the way concerns and complaints were responded to by government.

Sans Everything

In 1965 Barbara Robb, a psychotherapist, visited an acquaintance, Amy Gibb, in a long-term psychiatric ward in Friern Hospital, London, where she witnessed the abuse of patients, overcrowding and staff shortages. After failing to have the concerns she raised with hospital staff, the Regional Hospital Board (RHB) and NHS authorities acted upon, and discovering that this abuse was widespread, she founded Aid to the Elderly in Government Institutions (AEGIS), a small, elite pressure group. The group included Brian Able-Smith, an economist and professor at the London School of Economics.

Robb kept a diary of her hospital visits which she sent to the then Health Secretary Kenneth Robinson but again no action was taken. Following publication of a letter

about her experience to the *Times* published on 10 November 1965, Robb received hundreds of letters (Hilton, 2019). When again no action was taken, she published *Sans Everything: a case to answer* (1967). The book was a compilation of diaries, letters and testaments together with proposals for improvement from experts. One such proposal, put forward by Abel-Smith, was for an NHS inspectorate, ombudsman and a more effective complaints procedure.

In addition to exposing failures in care, and most relevant to the context for this study, was the exposure of the culture of fear that prevented patients, their relatives and staff from raising concerns, and the failure of the NHS, up to government level, to respond appropriately to concerns. Rather than instigate a public inquiry under section 70 of the NHS Act 1946 which would require an independent chair, or respond under the Mental Health Act 1959 where it is unlawful to mistreat a patient who is receiving treatment in a psychiatric hospital, the government established committees under the RHB chairs. Lacking independence, the inquiries were biased, witnesses felt intimidated and their testaments discredited, largely on the grounds they had no professional knowledge (Hilton, 2017). Upon the inquiries' conclusion the then Health Minister, Kenneth Robinson, announced that the allegations were 'totally unfounded or grossly exaggerated' (Hilton, 2017). However, there was a high level of media interest in *Sans Everything* and the press was critical of the Ministry's handling of the inquiries and dismissal of the allegations. This both strengthened public support of AEGIS and paved the way for others to raise concerns.

The Ely Inquiry

In 1967, Michael Pantelides, a nursing assistant in Ely Hospital, Cardiff, sent a letter to the *News of the World* about similar concerns of abuse to those raised in *Sans Everything*. (The letter can be found in Appendix 1 of the Ely Inquiry Report). Largely due to the campaigning work of AEGIS, the Ely Inquiry, while following the same procedures, adopted a more robust approach and many of the allegations were upheld. Of significance was the change in approach to witnesses as illustrated in the extract below which considers the testimony of witness XY.

“The whole subject of discipline needs to be considered together with the way in which complaints or incidents relating to the hospital were dealt with. Questions of principle and organisation are necessarily interwoven with problems of personality and leadership. There is, as it seems to us, much truth in XY’s thoughtful and understanding view that: “The senior staff were very

closely knitted together. One was saving the other from anything that might arise against one of them, and nobody had any chance of complaining”.

Report on Ely Hospital (1967)

However, while the Ely Inquiry had a more positive approach to witnesses, Michael Pantelides left Ely Hospital following a backlash of hostility from hospital staff (Hilton, 2019). In addition to recommendations for Ely hospital, the report made recommendations for the wider NHS including the review of the investigation of complaints which it said should also consider

“the establishment of an independent body that could, in the last resort, undertake consideration of complaints and disciplinary matters which had not been satisfactorily handled in some other way”.

Report on Ely Hospital (1967)

Sans Everything and the Ely Inquiry paved the way for a further wave of complaints and inquiries, a number of which made recommendations for improvements in complaint handling.

Consumerism in health care: Shifting power in the 1980s and 1990s

Powell and Greener (2009) outline two advances that shaped the relationship between public service providers and users.

Firstly, in 1990, under a Conservative Government, the National Health Service and Community Care Act (1990) introduced the internal market concept to the NHS across the UK, underpinned by the values of consumer choice and competition. The paternalistic culture evident in *Sans Everything* of deference to the medical professions and patients as passive recipients of care was shifting, with an increasing discourse of ‘consumers’ with rights. One of the underlying principles of creating the internal market was that patient choice would drive up the quality of care by making the threat of *exit* from those services providing lesser quality care improve standards. However, while the internal market created more choice at provider (general practitioner level) it had less impact on choice for individuals.

Secondly, the impact of the internet on access to information and knowledge has further changed relationships as patients become ‘informed consumers’ of health care able to challenge professional opinion (Powell and Greener, 2009). Langford *et al.*

(2020) report that the internet is the first place patients will go to when a health issue arises. They go on to say that while this can be an advantage and aid clinician-patient discussions, it can also lead to difficult conversations if patients are misinformed through the internet or have unrealistic expectations. Whilst accessing the internet can be empowering for some consumers of healthcare, limited or no internet access for others can increase health inequalities, with those with the most disadvantage having poorer health and most limited access to information. (Eysenbach & Jadad, 2001).

In 1991 the government published a White Paper '*The Citizen's Charter*'. The white paper was based around 4 themes: quality, choice, standards and value. In addition to a commitment to increase choice and privatisation where possible within public services, the White Paper proposed that each public service would be expected to develop and publish a charter that set out the standards of service citizens could expect from the service and inform them how to complain and to seek redress if those expectations were not met.

A charter complaints taskforce was established under the chair of Lady Wilcox to

- draw up and publish a set of principles for effective public service complaints systems that people can believe in.
- encourage public service organisations to adopt these principles where they do not already exist.
- review public service organisations' complaints systems.
- report to Ministers on the results of its work, and make recommendations: - on the effectiveness of public services' complaints systems; and, - on any further measures necessary to improve the ways in which public services respond to complaints (Seely et al., 1995)

In April 1996, following the report of a review committee chaired by Professor Sir Alan Wilson (Wilson, 1994) and the Government's response, *Acting on Complaints*, (March 1995), a new UK wide complaints procedure was introduced. The recommendations were accepted and introduced in Scotland through MEL (1995)⁷⁶ and interim guidance in 1996. The new complaints guidance introduced a stronger focus on local resolution, with progression to independent review no longer being an automatic part of complaints resolution. Along with the new guidance, extensive training on local resolution was delivered to front-line staff through a resource pack.

In 1999 and 2001, two large scale, UK wide evaluations of the NHS Complaints Procedure were carried out. Firstly, the Public Laws Project, supported by National Lottery funding published *Cause for Complaint?* (Wallace and Mulcahy 1999), followed by, *NHS Complaints Procedure National Evaluation* the Department of Health commissioned a further UK-wide evaluation of the new NHS Complaints Procedure (York Health Economics Consortium (YHEC) and NFO System Three Social Research (NFO STSR), 2001).

Both were large mixed method studies that distributed questionnaires and held interviews with a range of stakeholders including complainants, NHS staff, chief executives, conveners, Health Councils and patient interest groups.

The reports found that in the majority of cases complaints were not well handled with many complainants dissatisfied with the outcomes and left feeling distressed. This view was supported by complaints handlers who also felt the complaints process, while improved, needed to be simplified and with a focus on learning from complaints. While local resolution worked well in some areas, it was found to be dependent on the culture and level of education received by staff (YHEC and NFO STSR, 2001). Where it did not work well, local resolution was found to lack impartiality by failing to acknowledge the power imbalance between those complaining and the NHS. It also failed to demonstrate the accountability of the NHS (Wallace and Mulcahy, 1999).

There were concerns raised in both reports about primary care where a complaint might be perceived as a breakdown of trust (YHEC and NFO STSR, 2001) and where patients were fearful of being removed from the GP practice if they complained. (Wallace and Mulcahy, 1999; YHEC and NFO STSR, 2001).

Both reports found evidence that those making a complaint felt the independent review process was not independent enough and failed to hold the NHS to account.

The recommendations for improvement were extensive with 46 from Wallace and Mulcahy (1999) and 27 from YHEC and NFO STSR (2001) and covered procedural and structural changes aimed at improving the quality of complaint handling and enhancing impartiality.

More high-profile scandal – The Bristol Inquiries and Shipman Inquiries

In 2001 the Bristol Inquiry into the high mortality rates of babies following open heart surgery, led by Sir Ian Kennedy, recommended a reformed complaints procedure by

2002. In December 2004, Dame Janet Smith published her Fifth Report of the Shipman Inquiry *Safeguarding Patients: Lessons from the past - proposals for the future* which made further recommendations for complaint handling.

NHS Scotland: consumerism to partnership and patient/ public involvement

Health has been a devolved matter in the UK since 1999. While the fundamental principles of a service for all, free at the point of delivery remain, there has been an increasing divergence in policy (Timmins, 2013), including those policies relating to the management of complaints.

Although the internal market continues in the NHS in England, it was never popular in Scotland and was abolished in 2004, with the Scottish Government moving away from the notion of patients as consumers to that of a partnership approach to the delivery, management and improvement of health services, through greater patient/ public involvement and engagement.

NHS Complaints management in Scotland

In 2005, the Scottish Government established the Scottish Health Council (part of Healthcare Improvement Scotland and now Community Engagement) to promote patient focus and public involvement in health services, and in 2006, the Scottish Health Council and SPSO commissioned Craigforth, a social research company, to undertake a pilot study to examine the way patient complaints were being handled in Scotland.

Building on the pilot study, at the request of the Scottish Government, the Scottish Health Council commissioned Craigforth (2009) to undertake a review of the NHS complaints process in Scotland. One of the aims of this large-scale study was to identify ways in which barriers to complaining could be overcome. The study took a multi-strand approach, using qualitative and quantitative methods in three stages.

Stage one of the study began by mapping the complaints process. In stage two, a postal survey was sent to 8,000 people across 4 geographical NHS Board Areas, based on a random stratified sample drawn from the electoral register. A total of 1,664 (21%) responses were received. A separate postal survey was sent to all those (935) from across Scotland who had contacted the Scottish Public Services Ombudsman, of which 257 (27%) responses were received. Postal surveys were issued to the 449 GP surgeries in the 4 Board areas with 160 (36%) responding. All 22 NHS Boards were

issued with a survey about their complaint handling procedures with 14 (67%) responding and 82 complaints-handling staff from across Scotland with a total of 24 (29%) responses received.

In stage three, follow-up telephone interviews were conducted with 83 people drawn from the 1664 who responded to the population survey and focus groups were conducted with groups who were under-represented in the population survey.

The Craigforth (2009) study found that 69% of respondents in the population survey had never had cause for complaint with the NHS. However, of those that had, 53% had done nothing about the problem they encountered even when things had gone seriously wrong. Only 18% made a formal complaint with 27% giving feedback or expressing a concern.

A number of reasons for not complaining were identified with 'Wouldn't make any difference' (33%) and 'Might affect further treatment' (20%) being the top two, providing evidence that simply improving access to the complaints procedure may not result in those who are dissatisfied complaining.

In 2007, The Scottish Government published *The Crerer Review: The report of the independent review of regulation, audit, inspection and complaints handling of public services in Scotland*. The review found significant differences in complaints handling processes across public sector organisations and within single organisations making the landscape for those wishing to make a complaint overly complex.

Crerer (2007) made two recommendations that would overhaul the way public services, including the NHS in Scotland, would handle complaints

- A standardised complaints handling system should be introduced for scrutiny organisations and service providers in all public services; and
- The Scottish Public Services Ombudsman should oversee all public service complaints handling processes.

In 2011, the Patient Rights (Scotland) Act 2011 gave patients the legislative right to give feedback, comments, raise concerns and complain about the NHS. One of the main focuses of The Act is that NHS providers should learn from feedback, comments, concerns and complaints. The following provides a short summary of the difference:

- Feedback:** may be expressed orally or in writing, for example, in a questionnaire or survey
- Comment:** may be expressed orally or in writing and include suggestions or compliments. For example, on ward comments forms.
- Concern:** Concerns fall short of complaints as they are not expressions of dissatisfaction but rather, for example concerns about a specific treatment.
- Complaint:** may be expressed orally or in writing and is an expression of dissatisfaction about the service.

To support the implementation of The Act, the Scottish Government published ‘*Can I help you?*’ (2012) to aid

‘the development of a culture within NHS Scotland that actively encourages and welcomes feedback and views from its users in order to learn from their experiences. A culture that values all forms of feedback whether this is good or bad.’

(Scottish Government, 2012)

Alongside the Patient Rights Act (2011), the Scottish Government also published *The Charter of Patient Rights and Responsibilities* (2012) (updated in 2019) to further promote the rights of patients to give feedback and complain about their health care.

The model Complaints Handling Procedure

In 2012, the SPSO Complaints Standards Authority began working with a range of partners, including public representatives, to develop a standardised complaint system to be used across all public sector bodies in Scotland.

Major failings that influenced Scottish Policy: Mid-Staffordshire NHS Foundation Trust

In February the following year, the Mid Staffordshire NHS Foundation Trust Public Inquiry (2013) chaired by Sir Robert Francis, reported on one of the most serious failings in healthcare since the inception of the NHS. The inquiry and subsequent reports influenced complaint handling policy across the UK and beyond. Again, the failure of the NHS to listen to the voice of patients and relatives was central to the Francis Inquiry. Although decades apart, there are strong parallels with *Sans Everything* and the Mid-Staffordshire inquiry. At the forefront was Julie Bailie, whose

mother, Isabella Bailie, died in Stafford Hospital. Julie Bailie was a lead in developing the pressure group *Care for the NHS* that fought successfully to have a Public Inquiry into the failings at Mid-Staffordshire NHS Trust. Like Barbara Robb, she also suffered threats and intimidation during her campaign with the Trust attempting to discredit her account of the abuse patients were suffering in Stafford Hospital (Bailey, 2012).

In addition to Julie Bailie, Helene Donnelley, a staff nurse at Staffordshire, blew the whistle on poor standards of care in Stafford Hospital. Like Michael Pantalides in Ely, she also suffered bullying, intimidation and threats from colleagues as a result of the concerns she raised which led to her leaving the Trust. (Following the public inquiry, Julie Bailie was awarded a CBE and Helene Donnelley an OBE in recognition of their campaign to improve standards of care).

A whole chapter in the Francis Report (2013) is dedicated to the Trust's failure to listen to, investigate and learn from complaints. The failings at Mid-Staffordshire led to three further highly publicised reviews and reports that again had wide reaching impact on complaint handling policy and practice including in Scotland:

- *Review into the quality of care and treatment provided in 14 hospital trusts in England: overview report* (Sir Bruce Keogh KBE, 2013)
- *A review of the NHS Hospitals Complaint System: putting patients back in the picture* (Clwyd & Hart, 2013)
- *A promise to learn - a commitment to act* (August 2013) chaired by Don Berwick KBE, MD, MPP, FRCP President Emeritus and Senior Fellow, Institute for Healthcare Improvement. (Department of Health, 2013)

The reviews of the failings in Mid-Staffordshire were a turning point in the way patient feedback and complaints were managed. Moving away from simply reviewing the complaints process, themes from across the three reports included recommendations for improved leadership, listening and acting on feedback from patients and staff, transparency and the use of data for improvement – including data from complaints, and removing the culture of fear.

The quality of complaint handling in Scotland (2013 – 2016)

Around the same time two reviews of hospitals in Scotland were published by Healthcare Improvement Scotland *NHS Lanarkshire* (Healthcare Improvement

Scotland, 2013). and *Aberdeen Royal Infirmary* (Healthcare Improvement Scotland, 2014). Complaint handling was a feature in both reviews.

In 2013, higher than predicted level of mortality, measured by the Standardised Hospital Mortality Ratio (SHMR) led to a review of the safety and quality of care in NHS Lanarkshire's three acute hospitals. Patient experience of the acute hospitals in Lanarkshire was a significant part of the review, including the way NHS Lanarkshire managed complaints. The reviewers found that while some complaints had been dealt with sensitively and sympathetically, other responses were impersonal or defensive. Feedback from patients and the public indicated that many were not happy with the response they received.

The short-life review of quality and safety in Aberdeen Royal Infirmary was undertaken as a result of concerns raised with the Cabinet Secretary for Health and Wellbeing about the leadership, accountability and governance in acute services and the quality and safety within some specialties. In line with previous inquiries, a pressure group, Patient Action Co-ordination Team (PACT) that included patients and retired health care professionals, was also instrumental in voicing concerns about standards in Aberdeen Royal Infirmary. Part of the review looked at the quality of complaint handling against the government guidance '*Can I Help you?*' (2012) and found poor leadership and governance in the management of complaints and defensiveness in many of the complaint responses.

In 2014 the Scottish Health Council published their report *Listening and Learning: How feedback, comments, concerns and complaints can improve NHS services in Scotland*. This reported on a review of how well NHS Scotland was listening to patients and using their feedback to make improvements. In line with earlier research, the review found that there were still barriers to giving feedback or making a complaint, the main ones being:

- a fear of repercussions for their own or relatives' treatment
- not knowing how to make contact or who to make contact with, and
- a lack of confidence that anything will be done.

Whilst the review identified some progress towards improvement since the implementation of the Patient Rights Act (2011), it identified there was still significant room for improvement, making 48 recommendations around 3 key actions:

1. Remove the fear factor
2. Welcome feedback
3. Show the improvement

In December 2015, the SPSO published a report of an investigation into a complaint about NHS Borders. The report highlighted similar failings to those found in an earlier Healthcare Improvement Scotland Inspection of the care of older people in Borders General Hospital conducted in 2012. In addition, the SPSO found failings in the way NHS Borders had handled the complaint.

This prompted a further review by Healthcare Improvement Scotland, which was published in 2016, of the care of older people in Borders General Hospital which included an evaluation of the extent that NHS Borders had improved their management of, and learning from, complaints. The report acknowledged that significant work had begun in NHS Borders to improve the culture to one which welcomed complaints and the processes for managing them.

The Apologies (Scotland) Act 2016

When mistakes are made or patients have cause to complain, one of the things they want is a meaningful apology (Craigforth, 2006; SPSO, 2021). In their analysis of complaint responses, (McCreddie et al., 2021) found that where an apology was given it often took the form of a *'fauxpology'* stating for example 'I'm sorry *you feel*' (McCreddie, Benwell and Gritti, 2021 p8). The absence of an apology and acknowledgement that mistakes have been made can result in people seeking resolution through the legal process. While some staff may want to apologise because it is the morally right thing to do, they may have been prevented from doing so for fear of litigation. Litigation is not only costly in terms of time and finance, the stress of litigation can have long term adverse health implications for staff and patients (Maxwell, 2016).

In 2016, The Apologies (Scotland) Act received Royal Assent. Within the Act, an apology is defined as

“any statement made by or on behalf of a person which indicates that the person is sorry about, or regrets, an act, omission or outcome and includes any part of the statement which contains an undertaking to look at the

circumstances giving rise to the act, omission or outcome with a view to preventing a recurrence”.

The Apologies (Scotland) Act (2016)

The main aim of the Act was to bring about a change in culture by making it easier for frontline staff to apologise, promoting a more amicable resolution to disputes and thus avoiding the adversarial process of litigation (Maxwell, 2016). However, the Act does not make giving an apology compulsory or determine the level of apology that should be given. As Maxwell (2016, p 84) points out, not all apologies are created equal. A full apology captures the 4 Rs of apology; regret, responsibility, reason and remedy (SPSO nd). A partial apology may simply say ‘sorry you were hurt’ (Maxwell, 2016, p84) without acknowledging responsibility or giving a reason. Patients want more than words of regret, they want to see that responsibility is accepted and that change will be implemented to prevent future occurrences (Mazor et al., 2013)

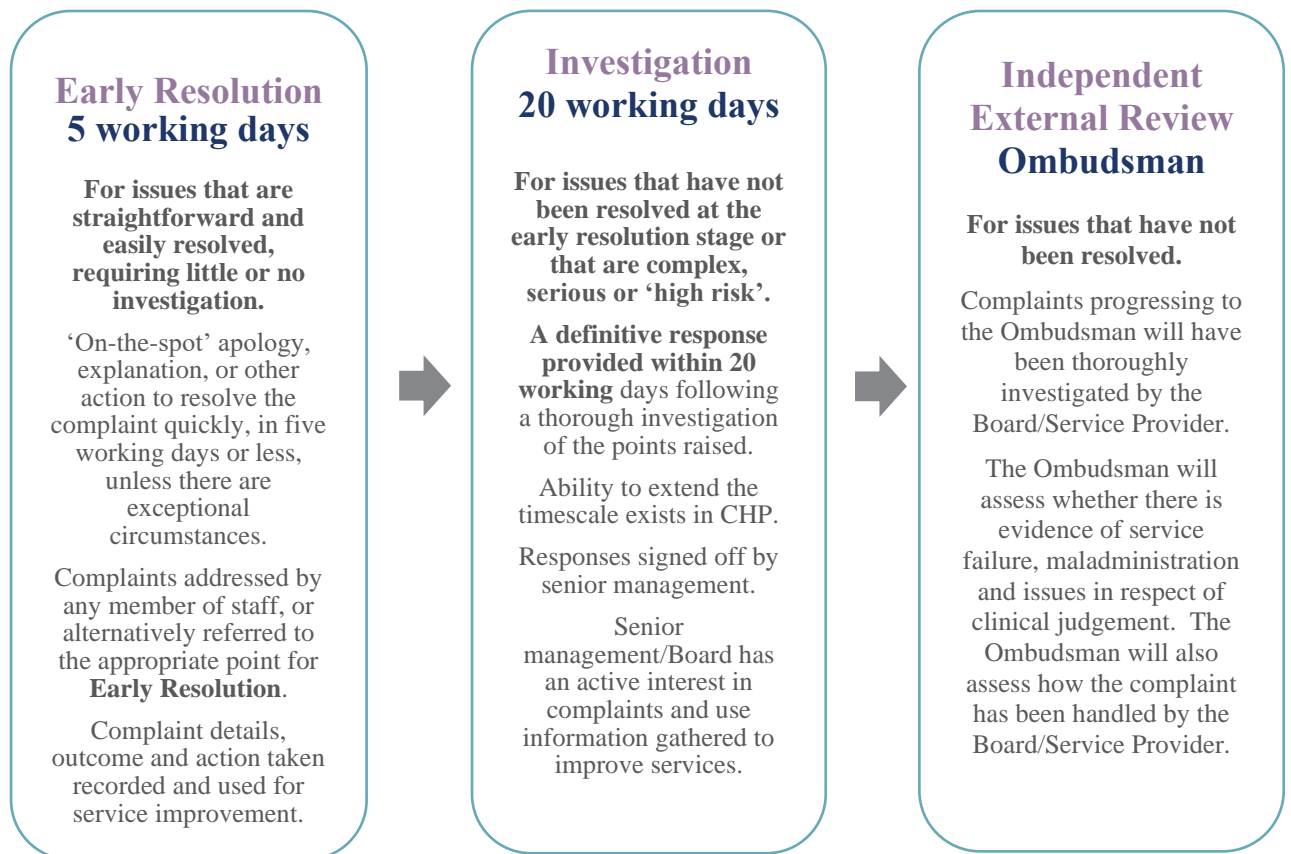
While not absolving individuals from liability, The Act prevents the action of making apology from being used in civil proceedings as an admission of liability. However, the while definition of apology within The Act includes regret and ‘looking at the circumstances that gave rise to the act, omission or outcome’ it is not explicit about the level of protection for full apologies that include responsibility and reason (Kleefeld, 2017). Concern remains that clinicians may be wary of offering a full apology (Leung & Porter, 2019).

Introduction of the Model Complaints Handling Procedure in NHS Scotland

On 01 April 2017, NHS Board Chief Executives were required to implement the Model Complaint Handling Procedure across acute and primary care services.

Figure 1: Diagram of the NHS model complaints handling procedure SPSO (2017)

The NHS Model Complaints Handling Procedure



A Scottish Government review of the first year of the introduction of the Model Complaints Handling Procedure (Bonello, 2019) found that it had been welcomed by NHS Boards and that there were signs of a move away from a blame culture, greater focus on the empowerment of frontline staff and better engagement with patients and families. The MCHPs were updated in 2019 and following publication under section 16B(5) of the Scottish Public Services Ombudsman Act 2002 on 31 January 2020, changes were implemented in April 2021.

1.3 Conclusion

In laying out as a chronology, the overview of major scandal, inquiries and subsequent reports since the sixties presents a picture of a shift in policy development and ambition

by successive governments. The ambition is now to create a culture where complaints are welcomed, investigated, responded to with an apology when they have been upheld, and a system that improves practice as a result of complaints. However, the evidence suggests that there is still some way to go to realise that ambition.

While many of the reports and reviews have highlighted the need to eliminate the pervading culture of fear, as Brennan (2013) highlights, the high profile and media interest in NHS failures can itself lead to a culture of fear where the lack of transparency in investigating and responding to complaints can feel challenging to those wishing to raise concerns. Fear may be compounded for the nurse participants in this study who, in addition to potentially coping with the barriers to raising complaints as a patient or relative, may be concerned about complaining about the organisation in which they work and the colleagues they work with.

In each of the inquiries outlined above, the voice of patients and staff has been instrumental in identifying and highlighting poor care. Nurse patients and nurse relatives are not just 'consumers' of the NHS, they work in the NHS. They are knowledgeable about healthcare and immersed in the culture and systems in which they operate. They are NHS staff with a unique perspective and insight of 'being on the other side'. If we could capture their experience of poor care when they find themselves in the role of patient or relative, as informed users of services, they may provide a unique insight and contribution to culture change and quality improvement before services reach the point of crisis.

1.4 Aims and Research Questions

Aim

The aim of this study is to identify the circumstances in which it would be easier for nurses who find themselves in the role of 'patient' or 'relative' to complain when they have received or witnessed care or treatment they feel could be improved.

Research Questions

The study is designed to answer the following two research questions:

1. What influences nurse patients' or nurse relatives' decisions about whether to complain about care or treatment they perceive to be poor?
2. What would make it easier for nurse patients or nurse relatives to complain about care or treatment they perceive to be poor?

1.5 Outline of thesis chapters

Chapter 2 presents a review and synthesis of the literature on the experience of nurse patients and nurse relatives.

Chapter 3 explains and justifies the theoretical choices that underpin this study.

Chapter 4 presents the research methods adopted. In this chapter, the rationale for using Reflexive Thematic Analysis (Braun and Clarke, 2013; 2022) is discussed and the approach to data collection, and sampling, justified. The ethical considerations and the steps taken to assure the quality and trustworthiness of the research are explained. I give a detailed account of my position within the study and my approach to reflexivity.

Chapter 5 outlines the complex process of analysis. It shows how the data were coded and how the codes were developed from an initial descriptive approach to the more analytical development of candidate themes.

Chapter 6 presents the findings from the final stage of analysis.

Chapter 7 provides a detailed discussion of the findings including how they relate to the research questions and to the current body of knowledge.

Chapter 8 makes recommendations for leadership, policy, practice and education. The thesis concludes with my final reflections.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

The purpose of this narrative literature review is to review and synthesise the available literature, and demonstrate that there is gap in knowledge about how nurses patients or nurse family members respond when they experience care that does not meet their expectations and therefore may give cause for complaint.

2.2 Aims of the review

1. To identify what is known about how nurses experience being a patient or family member of a patient
2. To identify whether there is evidence of nurse patients or nurse family members deciding to complain if the care they received falls below expectations

2.3 Types of review

There are many types of literature review available to present what is known about a field of study and justify the need for new research, with narrative (traditional), systematic (Cronin et al., 2008) and scoping reviews (Arksey and O'Malley, 2005) being three of the most common. The type of review undertaken will depend on the research aims and questions. For example, where the aim of the literature review is to evaluate all available evidence and make recommendations for practice, a full systematic review would be required.

Systematic reviews are held as the gold standard for literature reviews (Aveyard, 2010). They follow strict protocols such as those laid down by the Cochrane Collaboration to ensure a rigorous approach to identifying, appraising and synthesizing literature. Systematic reviews aim to minimise bias in the selection of primary research and ensure the robust quality assurance of studies selected for inclusion in the review.

A scoping study is a type of literature review where the emphasis is on mapping the extent, range and nature of research, rather than evaluating the quality of individual studies. Often conducted as a rapid review, scoping studies can be used to identify gaps where no previous research in a subject has taken place, or where the aims or research questions are not fully developed (Arksey and O'Malley, 2005).

Narrative (or traditional) reviews are often used as part of a dissertation or thesis where the aim is to identify gaps in knowledge, guide methodological decisions, and to provide justification for undertaking a study (Cronin et al., 2005). Whilst not following the detailed structure of systematic reviews, narrative reviews are still systematic in their approach. For example, being clear about the aims, inclusion and exclusion criteria can help to minimise researcher bias in the selection of articles. The consistent application of search terms and 'limiters' for database searches means that searches can be replicated (Aveyard, 2010).

2.4 Justification for undertaking a narrative review

The aims of this review are to identify what is known about the subject and justify the need for further research, rather than to evaluate evidence and make recommendations for practice. The rigour of a full systematic review is therefore not essential and is beyond the time and resource limitations of most single researchers.

In view of the possibility that no previous studies existed, a scoping review was considered for this study. However, despite initial challenges, relevant primary research studies were identified. In addition, the research had clear aims and research questions. The decision to undertake a scoping review was rejected and a narrative review was selected as the most appropriate approach. While not adhering to the strict guidance and rules that apply to a full systematic review, it was still important that a *systematic approach* was adopted to ensure that this narrative review had been undertaken in a rigorous manner. The following approach was adopted for this review:

- Identification of inclusion / exclusion criteria
- Identification of search terms
- Search of relevant databases: CINAHL Medline EBSCO, Ovid nursing, PsychInfo
- Search of reference lists
- Summarising the process of identification: PRISMA diagram
- Quality Assurance of studies included in review using CASP and supervision
- Synthesis of findings using thematic analysis

2.5 Inclusion and Exclusion Criteria

The inclusion and exclusion criteria are presented in **Table 1** below with a rationale for the decision:

Table 1

Inclusion	Rationale
Peer reviewed studies that report how nurse patients or nurse family members experience care	Peer review studies have undergone a rigorous quality assessment.
Peer reviewed studies that report on how nurse patient/ nurse family members respond to expectations of care not being met	Establishing what is known in my chosen field of study
Qualitative and mixed methods studies	Quantitative studies would not provide the rich data required to answer the review question
All date ranges included	Due to scarcity of literature no date parameters were set.
Exclusion	Rationale
Anecdotal accounts of nurse family / nurse family members' experience of care.	Lack of academic rigour.
Unpublished studies	Not been through the rigour of peer review.
Commentary and editorials.	Lack of academic rigour
Studies about nurse relatives experience of being the primary care giver to their family member	The review/ research question focuses on those nurses who have experienced care as a patient or relative in a healthcare setting.
Other studies, for example, those that were about staff experience or patients' clinical conditions.	Not relevant to the review/research questions
Those not available in English language	No access to translation facilities

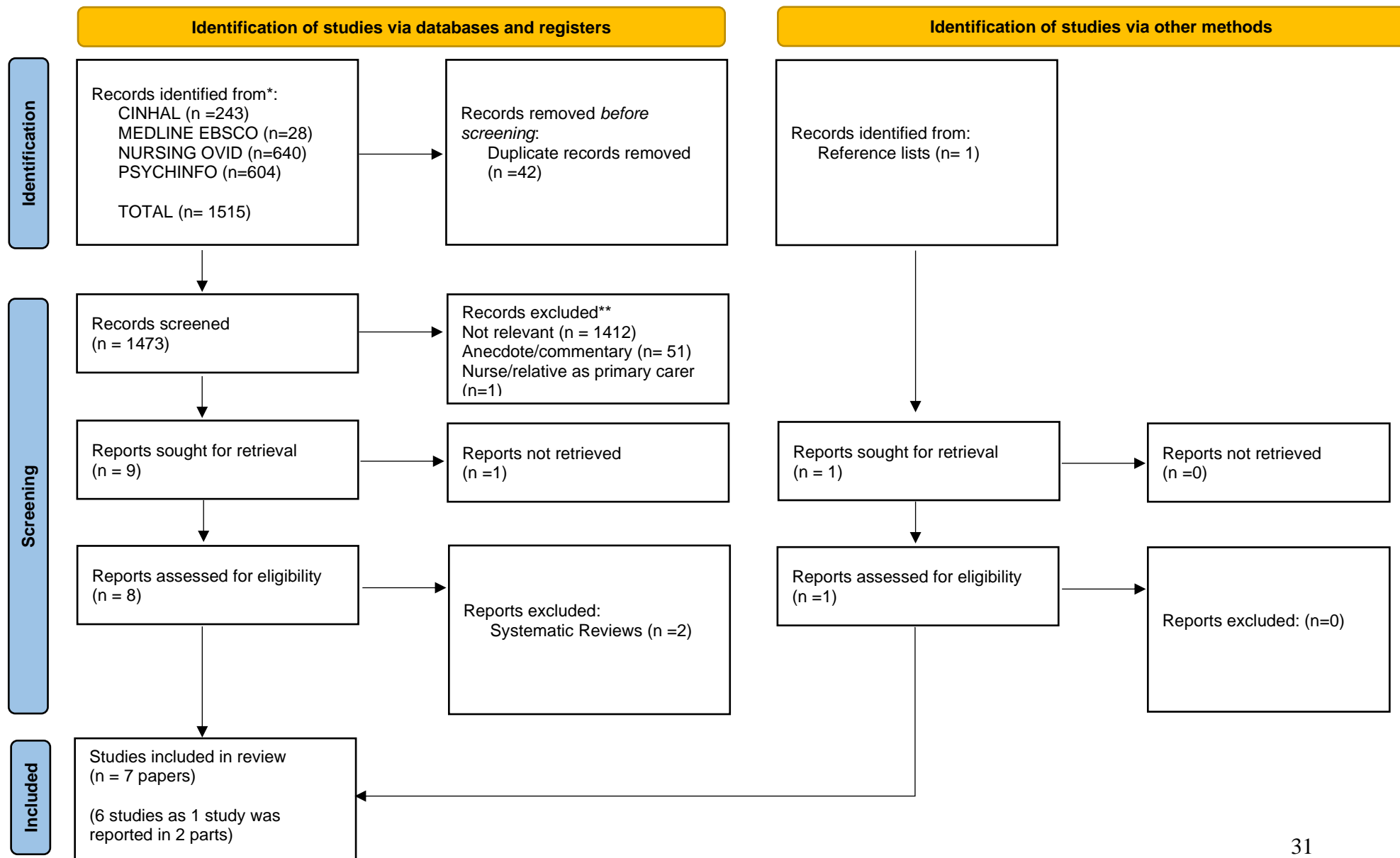
2.6 Identification of Search Terms

Searching and locating relevant literature was found to be challenging. The key words 'nurse', 'relative', 'patient', 'experience', 'dissatisfaction' and 'complaint' are common in most published articles in health journals, with 'complaint' often referring to specific health conditions rather than the NHS complaints procedure. Initial sweeps of Google Scholar, and full text, peer reviewed healthcare specific data bases including CINHAL, MEDLINE, psychINFO and Nursing OVID yielded in excess of 4 million articles. Combining those terms with Boolean Operators 'AND', 'OR' and 'NOT' did not narrow the result and continued to yield articles that were not relevant, mainly those relating to clinical conditions. Whilst the use of Medical Subject Headings (MeSH) terms are invaluable for searching clinical studies, they were not helpful for locating those studies that relate to patient or relative experience.

At this point the advice and support from Stirling University Library staff was invaluable. Within CINHAL 'nurses as patients' was found to be a key search term. Discussion with the librarian suggested that adopting the key phrases 'nurses as patients', 'nurses as relatives' and 'nurses as family members' across each of the relevant data bases may be a useful strategy. The librarian also suggested using the following terms and Boolean Operators: 'nurse AND patient' and 'nurse AND relatives' in the title only to narrow down and focus the search.

2.7 PRISMA flow chart

While PRISMA (Preferred Reporting Items for Systematic reviews and Meta-Analysis) flow charts are used to ensure the transparent and complete reporting of systematic reviews and meta-analysis, they are also useful for providing transparency in less structured reviews (Booth et al., 2022). The following PRISMA diagram in **Figure 2** summarises the process undertaken to identify and screen papers for inclusion.



In line with PRISMA guidelines, the search numbers from each individual data base were represented on the flow chart. Duplicate records were manually removed. During the screening process, titles and abstracts were read and assessed for relevance against the inclusion/exclusion criteria. Nine studies were sought for retrieval. One study published in 1997 was not available in full text and could not be sourced.

The database search identified two systematic reviews conducted of literature relating to nurses' experience of being nurse-family members of patients.

Positively, the two reviews confirmed the paucity of literature available about nurses' experience of being in a patient or family member role. However, discovering them presented a dilemma over whether to include these as part of the literature review. While systematic reviews and qualitative synthesis reviews are considered the gold standard in terms of evidence, they are also considered secondary data (Randolph, 2009).

The focus of each review was different to my own research and neither focused on the nurse's experience of being a patient. I was asking different questions of the literature and was therefore reviewing the papers through a different lens. Looking through the studies included in both reviews, not all had met the inclusion/ exclusion criteria for my own literature review. For example, I had excluded studies where the focus was on the nurse-family member's experience of being a caregiver rather than their relative being a recipient of care from health services. I had also excluded unpublished papers. For these reasons, I decided to include all the primary studies that fitted the inclusion criteria for my own study whether or not they had been included in the other two reviews. I then laid the reviews aside until I had completed my own thematic synthesis. I then compared the findings of my own review with both published reviews to identify any relevant additional themes.

Although 7 papers were identified, 2 were of the same study published in the same journal in 2 parts with different lead authors from the same research team. In the summary of papers, they are considered as one paper in 2 parts (Paper number 5a and 5b).

2.8 Limitations

It must be acknowledged that in not undertaking a full systematic review and given the challenge of finding appropriate key words and search terms for this subject, there is a risk that relevant research papers may have been overlooked. As a single researcher, I reviewed each of the studies for quality and inclusion. Although my decisions were discussed as part of my academic supervision, without a second researcher independently evaluating each of the studies, it is possible that my own bias influenced the final inclusion of papers.

Bias also needs to be considered in the analysis, particularly as some papers were identified after I had begun my own data analysis. In adopting a reflexive approach, I acknowledge that this will likely to have influenced the coding and theme generation within the review. The articles and reviews discovered after my data analysis had begun were incorporated into the findings and discussion chapters of this thesis.

2.9 Assessment of the quality of papers

There are acknowledged challenges to assessing the rigour and quality of qualitative research with debate regarding the use of checklists and tools and whether poor quality studies should be included in reviews (Lester & O'Reilly, 2021; Majid & Vanstone, 2018; Mohammed et al., 2016). Also, with the wide variety of approaches available to qualitative researchers it is difficult for novice researchers to have the breadth and depth of knowledge to make an evaluation of whether the ontological, epistemological and methodological decisions made by authors are consistent and appropriate in every study published. As qualitative studies are situated and context bound, (Thomas & Harden, 2008) suggest presenting a detailed table that summarises each study outlining the aim, sample, methods, and location (**Table 2**).

Thomas and Harden (2008) highlight the challenges in synthesising the findings from qualitative studies where there are different approaches, various reporting styles and representation of data. For this reason, Aveyard (2010) advises the use of a validated assessment tool to assess the quality of research papers as it acts as a guide to novice researchers and provides a consistency of approach. The Critical Appraisal Skills Programme (CASP) is the most commonly used tool for assessing qualitative research for inclusion in health-related qualitative synthesis and is approved by the Cochrane

Qualitative and Implementation Methods Group Guidance (CASP, 2018). The CASP tool consists of 10 questions based around 3 broad themes:

- Are the results valid?
- What are the results?
- Will the results help locally?

Each of the papers included in the review was assessed using the 10 questions contained within the CASP tool. The first 2 of the 10 questions are screening questions;

1. *'was there a clear statement of the aims of the research?'* and
2. *'is a qualitative methodology appropriate?'*

As all studies answered 'yes' to the screening questions, the remainder of the 10 questions were asked of each paper and the answers summarised on **Table 2** below. As a single researcher, to enhance the rigour of the review, the quality of each of the papers was discussed during supervision.

Table 2: Summary and quality assessment of literature

This table provides a summary of each of the papers included in the review. The rows highlighted in blue provide an assessment against of each of the elements in the CASP tool.

Author/ Year/ Country	Study Aim	Type/ Methods	Recruitment strategy and sample	Data collection	Researcher relationship/ Ethical Issues	Data Analysis	Main Findings Reported	Contribution
Paper1 Cohen M McQaid J Remington R 2021 USA	To identify experiences of nurses of being a patient or caregiver To identify assessments of the healthcare system by nurses	Qualitative and quantitative approaches Exploratory study	N=55 RNs convenience sample of RNs undertaking a degree programme Part 1 N=55 Part 2 N=45	Self- administered Questionnaire in 2 parts Part 1 measures assessment of healthcare system Part 2 describes experience	Professor left the room during consent process	Presented as 'results' . Both Qualitative and Quantitative questions-	<i>Assessment of the healthcare system</i> Majority said system performs well or very well Better communication and more resources needed to improve quality of care Improve accessibility and affordability <i>Experience of being a patient/caregiver</i> 96% felt the need to intervene in care because of their knowledge – 63% to prevent life threatening or significant complications 48.5% interventions met with a negative response from staff Need to translate for family members due to poor communication Adding professional insight can high	Findings used to form the basis of a larger, nation- wide study in the USA
Quality assessment based on CASP	Research goals were clear. Gap in knowledge /research identified	Qualitative methodology appropriate Also included quantitative methods (Likert scale) Exploratory study	Convenience sample – acknowledged in limitations	Appropriate for an exploratory study, Researcher developed questionnaire with expert input	Avoidance of coercion as above Ethical approval not discussed	Not clear from the paper how qualitative answers were analysed	Results presented as percentages with 'additional comments' summarised by the author Discussed in relation to research question/goals	As above – results to inform a larger study

Criteria met	Yes	appropriate– little previous research.	Yes	Yes	Yes/No	No	yes	yes
Paper 2 Elayan R Ahmad M 2017 Jordan	To examine nurses’ perceptions of ‘quality nursing care’ as recipients of care	Qualitative design with content analysis	Convenience sample of 231 RNs who had experienced hospitalization themselves or had a close relative within the last year. Recruited through response to poster advert in 8 hospitals	Self- administered questionnaire with 3 open ended Questions 1. Tell me about the evaluation of the quality of nursing care you received during your hospitalisation 2. How can nurses improve the QNC 3. Any other issues about nursing care?	Information sheet and consent form given to participants.	Content analysis. Frequency of key words/ phrases Text coded/ key words compared and grouped around similarities/ differences then organised into clusters. Then more conceptual and theoretical level	Analysis looks at frequency and themes reported in % numbers Reports 4 themes Improving nurses’ competency Continuing education Information based on scientific knowledge and evidence Serve with caring Treating the patient as human Involving patients in treatments Professionalism Communicating effectively Working as a team Fidelity in the profession Administrative factors More staff Following up on nursing care and patient problems	Recommendatio ns for practice discussed in relation to themes
Quality assessment based on CASP	Research goals were clear. Gap in knowledge /research identified	Qualitative design appropriate Research design	Large sample for a qualitative study.	Appropriate to aims, but paper talks about the design allowing for the study of a	Researcher role/bias not discussed Permission granted from relevant review	Methods for quality assurance and trustworthiness discussed. Description of analysis	Themes presented as a ‘% of respondents’ Although the paper states that during analysis data <i>moved to a conceptual and theoretical level</i> . The data	no new areas of research identified. No discussion of transferability to other

		discussed in the paper.	Recruitment strategy discussed	person's deepest thoughts, feelings, opinions and attitudes. Methods such as interviews may have given richer data.	boards and hospitals	process described	presented in the paper is largely descriptive. No limitations acknowledged in the paper.	populations or other ways the research may be used
Criteria met	Yes	Yes/Yes	yes	Yes	Yes/ No	Yes	No	No
Paper 3 Salmond S 2010 USA	To explore the experience of being a nurse family member of a relative hospitalized for a critical illness	Qualitative descriptive approach informed by grounded theory	N=22 Theoretical sampling Recruited through snowball technique	Open ended, unstructured interviews	Ethical approval obtained. Researchers position in the study evident	Constant comparative analysis – data collected and analysed simultaneously Confirmability and credibility through independent review and member checking	Themes Core theme – nurse role identity intertwined with their family member role identity and could not be separated (Conceptual model) Challenge: heightened emotional turmoil Challenge: required to be in charge Challenge: surveillance and protection Challenge: gaining information and seeking meaning Challenge: advocating for Challenge: resuming family roles Conceptual model presented.	Future research: \\ to examine critical care nurses' perceptions/ testing conceptual model Clinical implications: How to connect with nurse FM
Quality assessment based on CASP	Clear aim and justification for the study	Qualitative design appropriate	Detailed description of sampling strategy and recruitment	Setting and rationale for unstructured interviews explained in detail and justified	Relationship of researcher's personal experience to the RQs discussed Ethical approval obtained	In-depth description of the analytical process	Findings are explicit. Credibility discussed Findings are discussed in relation to the RQ Limitations acknowledged in the paper	Future research and clinical implications discussed

		Methodology appropriate and justified			Consent discussed			
Criteria met	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Paper 4 Duke J Connor M 2008 New Zealand	RQ How do the positions of senior nurses, who have experienced a life-threatening condition, influence the trajectory and outcomes of their illness journey?	Semi-structured in-depth interview Thematic analysis	N=11 Recruited through snowball technique (4) then email invitation to senior nurses (7) Participants had experienced a life threatening condition 1-10 years previously	Semi-structured in-depth interview Interview schedule given to participants in advance of interview 4 face to face 7 telephone	Ethics approval obtained Consent discussed including recording of interviews Also, identifiability could not be fully guaranteed because of the senior position of the participants	Thematic analysis – no detail as to how this was undertaken	Themes Looking after our own Gaze of family and friends in advocacy and intersection Stereotypes of nurses as patients Senior Nurses as vulnerable patients: Existential healing through the small things Senior nurses as knowledgeable people	Argue for careful care for all patients
Quality assessment based on CASP	Clear aims and objectives	Qualitative design appropriate for this study. The reason for the methods chosen not discussed in the paper	Detailed description of sampling strategy and how this was modified	Methods for data collection are explicit.	Consent discussed Consideration given to potential distress. Researcher role and bias not discussed	No in-depth discussion of the analytic process. No explanation of how the themes were derived from the data Contradictory data presented	Findings are explicit Credibility of findings not discussed Findings were discussed in relation to the original research question No Limitations acknowledged in the paper	Practice implications discussed No discussion of any future research or transferability of findings
Criteria met	yes	Yes/No	yes	yes	Yes/no	No	Yes	Yes

<p>Paper 5 a/b</p> <p>DeMarco R Picard C Agretelis J 2004 USA</p> <p>Part 2 Picard Agretelis Demarco 2004 (Findings published in two parts in the same Journal)</p>	<p>(Study published in 2 parts)</p> <p>Part 1 To uncover the dimensions of nurses' personal experience of cancer survivorship</p> <p>Part 2 To uncover the dimensions of nurses' professional experience of cancer survivorship</p>	<p>Interpretive Phenomenologic concepts from caring theory Watson (1990) and the theory of health as expanding consciousness.</p> <p>Exploratory study</p>	<p>N=25 Recruited through advertisements /posters. Sample size confirmed by previous similar studies.</p>	<p>Two face to face in-depth interviews in location of choice</p>	<p>Discuss caring as essential in co-operative enquiry. Researcher engagement - fully present</p>	<p>Thematic analysis</p> <p>Descriptive level themes</p>	<p><i>Part 1 Personal</i> Shock of becoming a patient Being nurse and patient: Asset or Liability Time (relating to cancer journey) Co-ordinating their own care The work to maintain normalcy Continuing need for support Uncertainty Non-clinical resources: attending to the whole self Survivorship as an opportunity</p> <p><i>Part 2 Professional</i> Five themes: Role ambiguity Deepening level of compassion for patients and others Self-disclosure as a therapeutic intervention Becoming an advocate for change</p>	<p>Part 1 Clinical implications: open conversations Including about control / discussion of nursing role, faith needs and how to give feedback if met with uncaring behaviours.</p> <p>Part 2 Future research on the relationship of social support to recovery; people > 5 years post recovery; and other cultures/ countries</p>
<p>Quality assessment based on CASP</p>	<p>Aims of the research clear</p>	<p>Qualitative approach appropriate</p> <p>Methodology justified in the paper</p>	<p>Recruitment strategy discussed – sample size based on previous studies using similar methods</p>	<p>Setting and method of data collection discussed and justified.</p>	<p>Researchers' position in the study discussed</p> <p>No comment in the paper about consent or ethical approval</p>	<p>Analytic process described.</p>	<p>Findings explicit and relate to RQs</p> <p>Rigour and trustworthiness discussed</p> <p>Limitations acknowledged</p>	<p>Clinical implications discussed</p> <p>Recommendations for future research</p>
<p>Criteria met</p>	<p>Yes</p>	<p>Yes/Yes</p>	<p>Yes</p>	<p>Yes</p>	<p>Yes/ No</p>	<p>Yes</p>	<p>Yes</p>	<p>Yes</p>

Paper 6 Zeit K 1998 Australia	To explore the experience of being a patient through nurses' eyes.	Hermeneutic phenomenology Thematic analysis	N=4 Nominal and purposeful sampling	Face to face unstructured interviews following a prompt question and follow up questions	Not discussed in the paper	Draws on a number of authors to aid analysis – describes the 6 steps taken	Themes Finding a balance Being in control Acknowledging me Spirit of caring The little touches Therapeutic environment I'll be back Expressing feelings I'd done wrong Being comfortable	Contribution to nursing knowledge: Illuminating the experience of nurses receiving nursing care. Offering insights into some essentials for quality nursing
Quality assessment based on CASP	Purpose clear within the text with rationale for interest in the area of study	Qualitative approach appropriate Rationale for methodology given with underpinning theoretical perspective	Explains why participants with knowledge were recruited (not where from).	Description given of how data were collected and justification given	Researcher relationship to participants not discussed Consent and information not discussed No specific comment on ethical approval but was undertaken as part of a Masters in Nursing	Detailed description of the analysis process	Findings clear Interpretation returned to participants to check accurate reflection	Contribution to knowledge stated
Criteria met	Yes	Yes/Yes	Yes	Yes	No/No	Yes	Yes	Yes

Table 3: Systematic Reviews

While not included in the review, the findings from the two systematic reviews supported the analysis of data from this research. The following table presents a summary of the two papers.

Study No	Author/ Year/ Country	Review Aim	Sample – number of papers included	Methods	Main Findings
3	Lines L Mannix T Giles T 2015 Australia	To increase understanding of nurse-parents experiences when their child is hospitalised with acute illness	16 articles 14 qualitative studies/ 2 mixed-methods 1998-2013	Literature review 2 Searches Experience of a nurse as a recipient of healthcare for him/herself or an adult relative The experience of the parent when their child is hospitalised for acute illness	No studies of nurse-parents identified. Review of nurses' experience as the recipients of healthcare and general public experience as parents of a hospitalized child (aims revised) <i>Search 1</i> Professional and personal boundaries <ul style="list-style-type: none"> • fear distress and disempowerment • using nurse persona for benefit of FM • HCPs placing NP/NCs in situations where they felt uncomfortable • Boundaries inseparable Advocacy <ul style="list-style-type: none"> • Compelled to advocate for FM due to nursing knowledge • Advocacy led to positive outcomes • Nurse FMs compelled to present themselves as non-critical and helpful Effect of dual role on care <ul style="list-style-type: none"> • Privileged and substandard care for NPs • Poorer care when staff felt intimidated by NPs in some studies not others • Issues of poor care in relation to the NP/FM role not fully explained by the current literature <i>Search 2</i> Parental emotional response Relinquishing control Parental perceptions of care

4	Giles T Hall K 2013 Australia	To interpret and synthesize nurse-family member experiences when a loved one is critically ill	7 articles 1999-2011	Systematic review using Thomas and Harden's approach to thematic synthesis of qualitative research	<p>6 themes identified</p> <p>Specialised knowledge</p> <ul style="list-style-type: none"> • Increased fear and anxiety • Ability to identify inadequate care • Seeking meaningful and specialized information <p>Dual-role conflicts</p> <ul style="list-style-type: none"> • Dual roles inextricably intertwined • Emotional cost of the dual role <p>Competing expectations</p> <ul style="list-style-type: none"> • Being all things to all people • Stepping in to provide omitted care and ensure care is adequate <p>Building relationships</p> <ul style="list-style-type: none"> • Building a relationship with staff • Adjusting their behaviour to be a model family member <p>Being 'let in'</p> <ul style="list-style-type: none"> • Watching over the patient • Advocating for the patient <p>Healthcare setting (own v other)</p> <ul style="list-style-type: none"> • Collegial support • Care needed with boundaries
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2.10 Overview of the quality of included studies.

All studies included in the review were qualitative apart from Cohen et al. (2021) who adopted a mixed methods approach. Their study asked two questions, with the question relating to the experience of being a patient or family member being answered through a qualitative approach.

As stated previously, assessing the quality of qualitative research can be challenging. Oftentimes the word limits and styles required by different publications limit the ability of qualitative researchers to report, for example, on approaches to reflexivity or the theoretical underpinnings of methodological choices made (Braun and Clarke, 2022).

Although the CASP guidelines do not advocate a scoring system, as can be seen in **Table 2**, all studies were assessed as providing enough evidence to respond positively to most questions within the tool. This suggests that while limitations were identified across each of the elements of the CASP tool, the overall quality of the studies supported their inclusion within the review.

The studies included ranged in date from 1999 – 2021. The findings from more recent studies resonated with those that had gone before, suggesting that the older studies were still relevant.

As can be seen from **Table 2**, the methods were varied and included thematic analysis, content analysis, descriptive analysis informed by grounded theory, hermeneutic phenomenology. Other than Duke and Connor (2008), all studies provided a rationale for the methodological choices made.

All studies described the recruitment process. Sample sizes ranged from n=4 to n=231 participants. In three studies (4 papers) the participants were nurses who had experienced being a patient (Duke and Connor 2008; DeMarco, Picard and Agretelis 2004; Picard Agretelis and DeMarco 2004; Zeitz 1999). In one study, the participants were nurse family members (Salmond, 2011) and in two papers, the sample included both those who had been nurse patients and those who had been nurse family members (Cohen et al., 2021; Elayan & Ahmad, 2017).

Data collection methods were varied with two studies using self-administered questionnaires, (Cohen et al., 2021; Elayan & Ahmad, 2017), two using unstructured interviews (Salmond, 2011; Zeitz, 1991), and two using semi-structured interviews.

Three studies included information about the researchers' position and relationship with participants (Cohen, McQuaid and Remington, 2021; Salmond, 2011; Demarco *et al.*, 2004). Three studies did not include whether ethical approval had been sought (Cohen, McQuaid and Remington, 2021; DeMarco *et al.*,2004; Zeitz 1999).

While three authors described in detail the analytic steps taken (Elayan and Ahmad, 2017; Salmond, 2011; DeMarco *et al.*, 2004), in the remainder, there was no information about how data had been analysed to generate the themes presented (Cohen, McQuaid and Remington, 2021; Duke and Connor, 2008; Zeitz, 1999).

In all studies, the findings were explicit. Most authors discussed the steps taken to assure the credibility and/ or trustworthiness of the research (Elayan and Ahmed 2017; Salmond, 2011; DeMarco *et al.*, 2004 and Zeitz, 1999). While most discussed the need for further research and implications for practice, few papers discussed the transferability of their findings. Only Salmond (2011) and DeMarco *et al.*, (2004) acknowledged the limitations of their studies.

2.11 Thematic synthesis

The synthesis was based on a modified version of Thomas and Harden (2008) thematic analysis. As the purpose of the review was to identify what is known and any gaps in the literature rather than to generate new findings or theory, the level of analysis generated descriptive rather than abstract themes.

Familiarisation

For thematic analysis, the first stage is immersion in the data (Ritchie *et al.*, 2014; Braun and Clarke, 2013; 2022). The selected studies were read several times during which initial impressions and thoughts were documented.

Coding

Codes were applied to sections of text within the 'findings' or 'results' sections of each study by annotating the margins on the paper. This involved studying the data that lay below the theme headings identified by authors. 75 initial codes were identified across the 7 papers. The paper number was annotated next to each code for ease of reference back to the data. This also enabled an 'at a glance' view of which codes were occurring across multiple papers. To keep the focus of the review on the aims set out, each code was then considered as to whether it potentially applied to Aim 1, Aim 2, or both, and again this was annotated. See extract below in **Table 4**.

Table 4: This table provides an extract of the codes identified from the papers linking them to the review question.

Paper Number	Initial Code	Potential review question
3	Role conflict	A1, A2
3,4,5a,6	Level of information important	A1, A2
3,4,5a	Lack of caring	A1
4,6	Preferential treatment	A1
4	Complaining = being vulnerable	A2
2	Not comfortable giving feedback	A2
4,5a,5b	Maintaining normalcy	A1

Each code identified was then placed on a 'Post-it' and grouped with 'like' codes. Grouped codes were reviewed and re-sorted.

2.12 Themes

Five themes were identified, and these are presented under two overarching headings in line with the review aims:

How nurse patients and nurse family members experience being on the 'other side of the bed'

1. *Role complexity and ambiguity*
2. *Expectations: Judging quality of care*

What do nurse patients and nurse relatives do when their expectations are not being met?

3. *Direct action*
4. *Speaking out*
5. *Using their experience to improve the quality of care*

How nurse patients and nurse family members experience being on the 'other side of the bed'.

Theme 1: Role complexity and ambiguity

With the exception of Elayan and Ahmad (2017) whose study focused on nurse patients' and nurse family members' perception of the quality of care rather than the wider experience of being a patient, the predominant, overarching theme across the other studies was the complexity and ambiguity participants experienced in occupying multiple roles.

In her study of nurse family members during the critical illness of a loved one, Salmond (2011) found that the nurse / family member roles were intertwined and could not be separated. For some nurse family members in the Cohen *et al.* (2021) study, this meant actively intervening when care was omitted. This is discussed further under the theme *direct intervention*. Only when the nurse family member had trust and confidence in both the staff and quality of care provided, could the nurse-self lessen, and the family member-self be allowed to come to the fore (Salmond, 2011).

One of the significant impacts of being thrust into the role of patient or family member was the loss of control participants experienced. Loss of control and trying to keep control was evident for both nurse patients and nurse family members in most studies (Salmond, 2011; Duke and Connor, 2008; DeMarco *et al.*, 2004; Picard *et al.*, 2004; and Zeitz, 1999). Nurses who were patients spoke of the shock of suddenly being in

that role (DeMarco *et al.*, 2004) and of the feelings of vulnerability that being ill and 'on the other side of the bed' invoked (Duke and Connor, 2008 and DeMarco *et al.*, 2004). In her study of 4 nurse patients, Zeitz (1999) reported that loss of control was mitigated when nurse patients had time to prepare for the role and were given adequate information.

For many, loss of control when combined with their clinical and insider knowledge led to heightened emotions, anxiety and fear of anticipating the worst. (Salmond, 2011; DeMarco *et al.*, 2004; and Zeitz, 1999). Fear of anticipation was particularly heightened when nurse patients or nurse relatives had to wait for care, or for information such as waiting for and anticipating a diagnosis (DeMarco *et al.*, 2004).

For some, role ambiguity was about how much they were expected to do in their patient or family member role. For example, Demarco *et al.* (2004) found that many nurse patients were having to co-ordinate their own care. Some nurses used their insider knowledge and access to IT systems to enable them to do this and valued the fact that they retained some level of control, but for others, they wanted to relinquish control and 'just' be a patient.

The relationships that nurse patients and nurse family members had with staff was an important feature of role ambiguity. Some spoke of staff being intimidated by or feeling uncomfortable at having to look after nurses and of the experience of being avoided (Cohen *et al.*, 2021; Salmond, 2011; Duke and Connor, 2008, Zeitz, 1999), while others felt being a nurse led to more positive and sometimes preferential treatment such as the allocation of a single room (Duke and Connor, 2008; Zeitz, 1999).

What mattered to the nurse patients and nurse relatives was being 'let in'; included as part of the team, working in collaboration, and being involved in making decisions. Family members who were let in were able to guard and protect their loved by being hyper vigilant and observant, and this helped to alleviate anxiety and maintain control (Salmond, 2011; DeMarco *et al.*, 2004). For those who were kept at arm's length, the experience led to increased anxiety and fear. Within the studies reviewed there was some evidence that nurse patients and nurse relatives who were recipients of care in their own workplace were more likely to be considered as part of the team than those who were not and where there were no pre-existing relationships (Salmond, 2011). Nurses who were cared for in their own workplace were also more likely to draw on the support of their network of colleagues.

Role ambiguity impacted on relationships with staff. Salmond (2011) found that nurse relatives actively tried to build relationships to gain better access to detailed, clinical information. In some studies participants recognised that staff could find it intimidating looking after other nurses (Salmond, 2011; DeMarco *et al.*, 2004) and deliberately modified their own behaviour to make staff feel at ease (Salmond, 2011). Others did not want to be seen as a 'know it all' or someone who makes a fuss (Duke and Connor, 2008; DeMarco *et al.*, 2004).

Relationships with participants' family members were also affected by role ambiguity. Nurse family members were often put into the role of nurse by the patient or other family members who wanted them to take charge (Salmond, 2011), and this often meant having to translate technical, clinical information (Elayan and Ahmad, 2017). For some, this put them in the position of outside expert with their family. For many nurses, role ambiguity also meant having to conceal their heightened fear and anxiety from family members (Salmond, 2011; Duke and Connor, 2008). For example, for some of the nurse patients in Duke and Connor's (2008) study this meant having to be strong for young family members and being brave in the face of a difficult diagnosis. Duke and Connor (2008) also found that boundaries were tested further for when there were multiple nurses in the family.

From across the studies it was evident that nurses as patients and family members struggled with role ambiguity. Many tried to maintain a sense of normality by working through their treatment, for example, doing paperwork during an infusion for cancer treatment (Picard *et al.*, 2004). Zeitz (1999) highlighted the need for closure and an end to the experience of being a patient.

Theme 2: Expectations: Judging the quality of care

There was evidence across the studies that nurse patients and nurse family members used their clinical knowledge and knowledge of the system to make judgements about the standard and quality of care they or their family member received. In their study that looked specifically at nurses' perception of the quality of care from the perspective of being a patient or family member of a patient in hospital, Elayan and Ahmad (2017) found that from their sample of 231 RNs responding to 3 open ended questions, only one third claimed that they had a positive experience of care with the majority evaluating the quality of care negatively. Cohen *et al.*, (2017) found that the majority of their 55 participants who completed Part 1 of their questionnaire evaluated care as

positive from a practitioner point of view. However, for those (n=44) who had also been patients or a family member and completed Part 2 of the questionnaire, the results were less favourable from a service user perspective, with 96% of participants feeling they had to intervene in the care being provided, based on their clinical knowledge.

What was evident in all studies was the unique perspective the nurse patients and nurse family members brought by drawing on both nursing knowledge and user experience. 'Stepping into the patients' world made the theoretical come to life for some participants' (DeMarco *et al.*, 2004: p525)

There was some evidence of nurses using their clinical knowledge to make judgements about the technical aspects of care, and the skill and competence of nurses (Cohen *et al.*, 2021). There was also some evidence of participants using their insider knowledge to judge wider, systems level issues such as nursing culture, leadership, and staffing levels (Elayan and Ahmad, 2017 and Duke and Connor, 2008). However, across all studies, most of the judgements made about the quality of care were about caring and uncaring behaviours.

Caring behaviours were judged to be those where participants were treated as individuals and included in decision making as part of the team (Elayan and Ahmad, 2017; Salmond, 2011; DeMarco *et al.*, 2004; Zeitz, 1999). Caring behaviours were also described as those where information was provided timeously and at the right level of clinical detail. For many it was '*the little touches*' as described by Zeitz (1991) that had the greatest impact; being treated with compassion, and nurses spending time and being present.

Uncaring behaviours were linked to role ambiguity and loss of control. These included having to wait for information and care, the tone and attitude with which information was delivered, and assuming clinical knowledge because of their nursing role. Staff feeling intimidated by caring for senior nurses led on one occasion to a senior nurse being avoided because of her role which resulted in more discomfort and her prolonged illness (Duke and Connor, 2008).

What do nurse patients and nurse family members do when their expectations are not being met?

Theme 3: Direct action

There was some evidence that nurse family members took direct action when standards were not being met, intervening to prevent harm and to advocate for their loved ones (Cohen *et al.*, 2021; Salmond, 2011; Duke and Connor, 2008). Where direct action was taken, most nurse family members felt that it had resulted in positive outcomes for the patient (Cohen *et al.*, 2021; Salmond, 2011). While some staff reacted positively to interventions and were receptive to input from nurse family members, many staff responded negatively, indicating that the nurse family members had overstepped the mark (Cohen *et al.*, 2021; Duke and Connor, 2008)

DeMarco *et al.*, (2004) described distress amongst participants who found staff to be uncaring and lacking in compassion with some switching providers to ensure care was given competently and compassionately. This was the only study to report 'exit' as a response to poor quality care.

Theme 4: Speaking out

There was evidence that some nurse family members felt it was their role to speak out and advocate for the patient when care was not meeting the standard expected (Cohen *et al.*, 2021; Salmond, 2011). However, like those who intervened, this was sometimes met with a negative reaction and a reminder from staff that they were a family member and not there in a nursing role (Salmond, 2011).

Although all studies found negative aspects to the care received, Duke and Conner (2008) were the only authors to discuss complaints in their findings. They found stereotypes within the participants stories of nurses as complaining patients who might receive compromised care if future treatment was required. Participants were also concerned that if they complained they may compromise future working relationships with colleagues. Two participants did write a letter of complaint but overall, complaining made the senior nurse patients in the study feel vulnerable.

Theme 5: Using their experience to improve care

Only two studies reported the action taken (Picard *et al.*, 2004) or suggestions by participants (Elayan and Ahmed, 2017) to improve the quality of nursing care within the findings.

Picard *et al.*, (2004) found that the cancer experience changed participants view of the wider healthcare system and their professional role within it. Participants used self-disclosure about their illness judiciously to support patients going through a similar experience. Others fulfilled an advocacy role at practice and systems level, for better practice. Participating in the study was also seen by some as contributing to improvement by sharing their stories.

Elayan and Ahmad (2017) identified 4 themes as suggested methods/ areas of focus to improve the quality of nursing care: Improving competence through training and education; treating the patient as human and building relationships with families; professionalism and effective communication and administrative factors such as better staffing levels and resources.

2.13 Discussion

The findings from this review suggest that with only six studies (7 papers) of varying age, size, and quality, the evidence of the experience of nurses as patients and family members of those who are patients is limited. From the evidence that is available, the experience is clearly complex with nurses occupying, and sometimes struggling to manage multiple, intertwined roles. There is consensus that nurse patients and nurse relatives experience care differently from lay people and have unique needs.

While the findings of this review suggest that there is some evidence that nurses in the role of patients or family members use their nursing clinical knowledge and insider knowledge of the system to assess the quality of care, there is little evidence as to whether, or how, nurses complain when the quality of care they receive does not meet the standard they expect.

The evidence suggests that nurse patients and nurse family members will challenge staff directly and/or intervene when they judge standards have not been met. However, there is also some evidence that nurse patients and nurse family members are reluctant to complain, fearing that to do so would impact on future care. Without that information being captured at system/organisational level, opportunities for learning are lost.

Review of the two qualitative systematic reviews of the experience of nurse-family members (Lines et al., 2015) and nurse- parents (Giles & Hall, 2014) did not yield any additional themes. As with the later papers included in the literature review, the recommendations from the reviews were woven into the analysis and discussion chapters of this thesis.

2.14 Conclusion

The limited evidence available suggests that with their ability to judge standards and quality of care using their clinical and insider knowledge, nurse patients and nurse family members could be an invaluable resource for quality improvement. It also suggests that nurse patients and nurse family members are reluctant to complain. This is in line with research findings that report the behaviour of non-nurse patients and family members when they receive care that does not meet their expectations (Craigforth, 2006).

The literature review supports the need for this study by identifying that there is limited evidence on the experience of nurses as patients or family members. It has also identified there is a gap in the literature about what would make it easier for nurse patients or nurse family members to complain if the quality of care they receive fails to meet their professional expectations.

Chapter 3: RESEARCH THEORY

3.1 Introduction

In this chapter I explain and justify the theoretical choices that underpin the study.

The research questions are:

1. What influences nurse patients' or nurse relatives' decisions about whether to complain about care or treatment they perceive to be poor?
2. What would make it easier for nurse patients or nurse relatives to complain about care or treatment they perceive to be poor?

Braun and Clarke (2013) suggest that qualitative research approaches ask the reader to consider how findings may relate to their own situation or practice. It is my hope that this study will expand the body of knowledge about how nurses experience care and how, when things go wrong, we can harness that experience to improve patient care. However, there is no one definition or identified correct way to undertake qualitative research. There are a myriad of often polarised views and stances which characterise qualitative research (Blaikie, 2007; Crotty, 1998; Denzin and Lincoln, 2011; Silverman, 2010), with some commentators advocating a rigid adherence to a particular doctrine and others advocating a more pragmatic, flexible approach (Robson, 2011; Guest, MacQueen and Namey, 2012). If research is to be accepted by the reader as ethical and credible, and its claims worthy of having wider generalisability or applicability, it is important that the researcher clearly documents and defends the methodological choices made and the philosophical stance which lies behind those choices (Crotty, 1998). I begin by defining the type of research I have undertaken.

3.2 Type of research

The type of research undertaken is determined by the research question(s). Brewer (2007) describes four types of research:

- Exploratory
- Descriptive
- Analytical
- Predictive

Exploratory research is undertaken when there is little known about a subject or not enough is known about a subject to enable the formulation of a hypothesis (Brewer

2007). As discussed in Chapter 2, there are few studies about nurses' experience of being patients or patient's relatives, and none that focus specifically on nurses who have had a poor experience of care, therefore, to some extent, my research is exploratory. However, I am not looking to generate data to formulate a hypothesis which can be tested in a future study, nor am I aiming to test whether the methodology adopted could be used in a larger study.

Descriptive research often involves answering research questions that ask '*What?*'. '*What?*' questions are directed towards discovering and describing the characteristics of, and patterns in, social phenomena (Blaikie, 2007, Brewer, 2007). Although both my research questions ask '*What?*', I aim to go beyond providing a detailed description and categorisation of data, to exploring patterns and meaning and providing explanation. According to Ritchie *et al.* (2014, p.32), '*What?*' questions are also posed in explanatory research, for example, when the researcher is trying to explain the motivations that lead to decisions, actions or non-actions. Explanation requires more than description; it requires analysis of data. The type of research I am undertaking is therefore analytical. I am not trying to predict future complaint behaviour.

Having decided on the area of interest, developed the research questions and determined the type of research, I was faced with a number of choices and decisions regarding the approach to my research. Blaikie (2007) advises that the researcher should undertake a process of weighing up the strengths and weaknesses of available options in relation to a particular research problem.

The first, and most challenging dilemma was the range of ontological (what exists) and epistemological (theory of knowledge) assumptions described and debated within the research literature (Blaikie, 2007; Crotty, 1998; Denzin and Lincoln, 2011; Hammersley, 2008).

Theories and philosophies concerned with the nature of what realities exist and how we can know and learn about these realities are complex, and the extent to which researchers need consider these issues is debated. Much of this debate centres on the nature and purpose of the research and whether it is *theoretical* (pure) or *applied* research. Theoretical research is described as that which is driven by curiosity and focuses on expanding knowledge or thinking within a certain discipline, whereas applied research is that which focuses on finding solutions to practical problems (Guest *et al.*, 2012, Ritchie *et al.*, 2014). As this research is undertaken as part of a Clinical

Doctorate Programme, the focus is on making a difference to practice, rather than purely furthering knowledge itself. It is also essential that this study meets the academic requirements of the programme through presenting a well-designed study with credible findings.

In undertaking research to solve 'real world' problems, authors such as Robson (2011), Ritchie *et al.* (2014), and Guest *et al.* (2012) hold the view that while theoretical or philosophical perspectives form a basis for enquiry, the most appropriate methodological approach is the one which best addresses the research problem. However, there are criticisms of this 'pragmatic' approach. Adopting a range of approaches selected to suit an individual research question risks the view that 'anything goes' (Mason, 2002), and that the potential lack of consistency between ontology, epistemology, theoretical stance and methodology threaten the validity, reliability and credibility of the research.

Regardless of where the research sits in terms of being theoretical or applied, having an epistemological and theoretical perspective is important as it helps the researcher to develop the most appropriate design for the research objectives and will influence decisions on the kind of data being gathered, how it will be gathered and how it will be analysed (Gray, 2014)

Crotty (1998) highlights that one of the major challenges for many researchers is the range of interconnected theories and stances within the literature and the diverse use of terms which in some cases are interchangeable and in others, the same term is used in sometimes contradictory ways. As an inexperienced researcher, I found my thinking being challenged in a way I had not experienced before.

3.3 Ontology and Epistemology

Ontology (what is reality?) and epistemology (what can we know about reality and how is that knowledge produced?) underpin all research.

Ontology

Ontology is about 'being' and the nature of reality and what exists. In justifying the ontological position for this study, I focus on the two polar beliefs about the nature of what exists: *realism* and *relativism*.

Realism

A realist perspective adopts the position that there is one single reality or truth that is waiting to be discovered. Here, the researcher is objective and independent of the research process. A realist ontology is commonly associated with positivist enquiry but is also evident in some qualitative research, for example, it is the ontology that underpins some forms of thematic analysis where coding reliability is a key feature of the analysis (Braun and Clarke, 2022).

Relativism

Unlike realism, a relativist position rejects the notion of one single independent reality or version of the truth, holding a belief that there are multiple realities. Relativism relies on human interpretation of the data, rather than a true and accurate account. The researcher is part of the data collection process; the influences of the researcher's values, beliefs and life circumstances on the research are valued and acknowledged through reflexivity. (Braun and Clarke, 2013; 2022).

My ontological position

The ontological position is determined by the research question. For example, if the research question for this study was seeking to measure the quality of care nurse patients had received, it could be measured against agreed standards. The reality of 'quality of care' could be observed by others; by multiple researchers, having been assessed for interrater reliability, using the same metrics. Reality in this scenario exists outside of the mind and would adopt a realist or critical realist ontology.

However, for this study, the question is asking '*what influences?*' and '*what would make it easier?*'. The meaning the nurse patients and nurse relatives attribute to their experience and decision making is held in the minds of the participants. As the researcher, I sought knowledge of that reality and in order to do so, would involve me as the researcher interpreting that reality. If others were to undertake the same research, they may interpret that reality through a different lens and have a different perspective. This research is therefore underpinned by a relativist ontology.

Epistemology

Blaikie (2007:18) suggests that a way of thinking about epistemology is in terms of the relationship between the researcher and the 'things' of which they wish to have knowledge. Blaikie (2007) goes on to say:

“These ‘things’ or objects can be regarded very differently, fundamentally as either real or ideal, as having independent existence or simply being ideas”.

Blaikie (2007, p18)

The epistemological stance adopted will therefore be determined by the researcher's view of what knowledge is possible. As it is inherent within the theoretical perspective, and therefore in the methodology, the stance the researcher takes will impact on how the research is undertaken and how the research outcomes are presented. There are many different epistemological stances described in the literature. Crotty (1998) describes three:

- Objectivism
- Subjectivism
- Constructionism

With *objectivism*, linked to positivism and post-positivism, reality exists independent of consciousness. Researchers who hold this view are looking to discover the objective 'truth' through discovering this meaning; meaning that has been there all along waiting to be discovered. (Blaikie, 2007; Crotty, 1998; Gray, 2014)

In *subjectivism* (linked to postmodernism) meaning does not come from the relationship between the subject and the object. Meaning is not constructed, it is imposed on the object by the subject. The meaning is 'imported' from somewhere else such as dreams, from the collective unconscious, religious beliefs or '*anything but an interaction between the subject and the object to which it is ascribed*' (Crotty, 1993, p9).

The terms *constructionism*, *constructivism* and *social constructionism/constructivism* are found in the research texts with different authors applying different meaning (Blaikie, 2007; Creswell, 2009; Crotty, 1998). Constructivism, according to Crotty (1998), is a term which focuses on '*the meaning making activity of the individual mind*' (Crotty, 1998:58) where as social constructionism holds that our culture shapes the way we see and feel things, and where meaning is shaped by our language and other social processes. Creswell (2009) refers to the latter as *social constructivism*. To aid clarity, I use the term 'constructionism' throughout this section by which I mean:

“the outcome of people having to make sense of their encounters with the physical world and with other people”.

(Blaikie, 2007:22).

Constructionism acknowledges that objects (such as trees) exist before they are discovered by people, but that the meaning of an object can only be socially constructed. This social construction of meaning may be different for individuals depending on the culture and context in which they are living.

When undertaking research from this perspective, the goal of the researcher is to rely as much as possible on the participant's view of the situation being studied using open ended questions to enable participants to construct meaning from their experience, capturing the complexity of their views not just a few categories or ideas (Creswell, 2009, p8).

Constructionism can be applied to both participants and researchers. Participants '*conceptualise and interpret their own actions and experience, the actions of others and social situations*', while researchers '*socially construct their knowledge of social actor's realities, their conceptions and interpretations of the actions of social actors and of social situation.*' (Blaikie, 2007, p23). This notion is helpfully summarised by Lincoln, Lynham, and Guba (2011) as:

"This [constructionism] means we are shaped by our lived experiences, and these will always come out in the knowledge we generate as researchers and in the data generated by our subjects".

Lincoln, Lynham, and Guba (2011, p104)

Researchers with this view position themselves in the research to acknowledge that their own cultural, historical experiences and background will shape their interpretation of their participants views of the world (Creswell, 2009).

My epistemological stance

The 'things' I wish to have knowledge of are the influencing factors which would lead nurses to decide whether to complain or say nothing if they had received or witnessed poor care and what, if anything, would make it easier for them to complain.

I am not looking for a single, verifiable 'truth' waiting to be discovered through positivist, scientific means. The reality I am seeking is constructed by the nurses who have experienced or witnessed poor care in their role of patient or relative. I aim to construct meaning from their accounts. Given the duality of their role as nurses and patients/relatives, historical and cultural influences will have shaped their experiences

and the way they feel about their experiences. I acknowledge that my own role as the researcher and a nurse, and my situation within the research is important to the interpretation and analysis of the data generated from interviews with the participants, and I consider this further in Section 4.9 where I discuss the role of reflexivity. This is consistent with a social constructionist approach and congruent with a relativist ontology and the notion that reality is constructed and interpreted from experience and social interaction.

3.4 Theoretical Perspective

In describing their theoretical perspective, researchers are clarifying their view of the human world, and the social life within that world, and setting out the assumptions they bring to their research methodology (Crotty, 1998). 'Different ways of viewing the world shape different ways of researching the world' (Crotty, 1998, p66).

For Crotty (1998) the debate is about positivism (and post positivism) and non-positivism (for example, *interpretivism*, *critical enquiry*, *feminism*. and *postmodernism*), not about quantitative v qualitative methods. It is possible for qualitative research to be situated within a positivist stance; it is not the methods that define the work as positivist, but the presentation of the findings as objective, valid and generalizable. Crotty (1998) argues the distinction between qualitative and quantitative research occurs at the methods level, not at the epistemological or theoretical perspective levels.

It was therefore not as simple as deciding that a qualitative approach was the best fit for my research questions, I had to consider my theoretical perspective. In doing so I considered the two main philosophies: positivism/post-positivism and interpretivism.

Positivism/ Post-positivism

The word positivism was first attributed to Aguste Comte and originated in Comte's desire to further social reform through embracing one scientific method that could be applied in many contexts across the natural and social sciences. The main feature of this one scientific method was one of *laws* which can be established scientifically through observation, experiment and comparison (Crotty, 1998 p22).

The philosophy of *logical positivism* was developed by a group of philosophers in the 1920's known as the Vienna Circle. The Circle developed the view that truth could only be verified through knowledge derived from science. Their view was that factual,

verified, knowledge is that which is experienced through our senses, either directly through sight, touch, smell or through the instruments of science. The logical positivist view is that although metaphysics, ethical values and religion may hold important emotional or spiritual value, they cannot be verified scientifically.

Positivism today retains the standpoint that there is a distinction between knowledge that is empirically verifiable and that which is subjective, and between fact and value. One of the criticisms of the positivists view is their belief that scientific knowledge is completely objective, valid, certain and accurate. This led to the development of *post-positivism*.

In the early 1900s scientists studying sub-atomic particles were challenged both ontologically and epistemologically by the notion of absolute certainty. Sir Karl Popper (1902-1994) introduced the notion of falsification as opposed to verification. This view holds that all observation, including objective reality is fallible. Absolute truth would require every possible object to be observed. As this is not possible, we cannot be certain that one variation exists. Therefore, scientists cannot prove a theory, they can only make a hypothesis which they then try to prove false and reject (Creswell, 2009; Crotty, 1998).

The shift in thinking about absolute certainty was furthered by Thomas Kuhn (1922-96) who, after historical review, presented the thesis that scientists operate within a set view of the world or *paradigm*, and that new ways of viewing the world create a paradigm shift, thus further challenging the value-free objectivity of scientific discovery (Crotty, 1998). The postpositivist view has moved away from the absolute certainty of positivism to *a certain level of objectivity and probability*.

Interpretivism

Interpretivism, which is closely linked to a constructionist epistemology, was developed as 'anti-positivist' in an attempt to explain human and social reality (Gray, 2014). Unlike positivism, interpretivism does not adopt an objective, value free stance. The interpretivist approach '*looks for culturally derived and historically situated interpretations of the social life-world*' (Crotty, 1998, p67).

The roots of interpretivism are associated with Max Webber (1864-1920) who described the human sciences as being about *Verstehen* (understanding) and the natural sciences about *Erklären* (explaining) (Crotty, 1998). Where the natural

sciences focus on laws and consistency, the social sciences focus on individual lived experience, and understanding the role context and culture play in that experience (Blaikie, 2007; Crotty, 1998).

Over the centuries there has been ongoing debate as to how different the research methods used in the natural and social sciences ought to be. However, it is now the generally accepted interpretivist view that the human and social sciences require different methods from the natural sciences leading to the distinction between qualitative and quantitative research methods (Crotty, 1998, p71).

My theoretical Stance

I am interested in understanding how the participant's dual role of nurse and patient (or relative) has influenced their decision about whether to complain about care or treatment they perceive to be poor. I am also seeking to understand what would make it easier for them to complain about care or treatment they perceive to be poor. I am interested in the culture and context within which these experiences have occurred. In line with the relativist ontology and constructionist epistemology, my research is therefore framed within an interpretivist stance.

3.5 The research approach: Logics of Inquiry

Another important question for researchers is; '*is the logic used to answer the research question congruent with the ontological and epistemological approaches within the study?*', as this will influence decisions on sample size, and type and level of analysis. Inductive and deductive forms of reasoning are the two dominant styles presented in the literature. Inductive logic (discovery) involves a bottom up approach to building knowledge, starting with data/observation and concluding with theory/explanation. Although inductive reasoning can be used in quantitative research, it is usually associated with qualitative research. Deductive logic (proof) is top down, using evidence to test a pre-existing theory and hypotheses which will either be confirmed or rejected. Based on *falsificationism*, it is usually associated with quantitative research (Blaikie, 2007). It is rare to find studies that are purely deductive or inductive and commonly researchers use a combination at different points in their research.

My approach

As can be seen from the literature review, there are very few previous studies that relate directly to my research question, which suggested an inductive approach, beginning with the data, may be appropriate for my research. However, my approach is not purely inductive. There are studies that look at complainant experience and studies that relate to nurse's experience of being a patient, so there was some broadly relevant evidence to draw on. In addition, I was able to draw on my personal knowledge and experience as a senior nurse managing complaints. For example, the development of the semi-structured interview proforma was devised in part from the available literature and part from my experience informing what I wanted to know.

3.6 Experiential and /or Critical orientation?

Having decided on a qualitative approach, another important theoretical consideration was whether the orientation of the enquiry was *experiential* or *critical* (Braun and Clarke, 2013; 2022). Experiential qualitative approaches are those which focus on people's experience and how they feel and think about that experience. Critical qualitative approaches are those which focus on how people interpret and construct meaning from their experience. As a researcher, adopting a critical orientation means '*interrogating and unpacking patterns of meaning*' (Braun and Clarke, 2022). Being clear about adopting a predominantly critical orientation at the outset was important, not just to add to the clarity and aid congruence of the theoretical underpinnings of the research, but to keep the analysis focused on the research question, which was not just about understanding participants experience, but about how they responded and made the decision to complain.

3.7 Hermeneutics: The theory of interpretation

Closely related to the orientation of the research is the theory of how interpretation leads to understanding, or Hermeneutics. Hermeneutics originated with interpretation of the Bible and classical texts. In contemporary philosophical hermeneutics, developed by scholars such as Schleiermacher (1768-1834), Dilthey (1833-1911), Heidegger (1889-1976) and Gadamer (1900-2002), Ricoeur (1913-2005) hermeneutics moved beyond the interpretation of the Bible and the classics to any text, the spoken word and art (Schmidt 2006).

An in-depth exploration and critique of hermeneutics are beyond the scope of this thesis. However, the following two areas are relevant to this study:

- Ricour's (1970) two forms of hermeneutics: *empathy and suspicion*, and
- consideration of how the hermeneutic circle influences and supports analysis.

Empathic and Suspicious Interpretation

Paul Ricoeur was an eminent philosopher and prolific writer. In his essay *Freud and Philosophy: an essay on interpretation*, Ricoeur (1970) presents two forms of interpretation: a hermeneutic of faith (or empathy) and a hermeneutic of suspicion. Willig, (2017) and Braun and Clarke (2022) discuss how these two hermeneutics are applied to interpret data in qualitative research. It is important to note that the terms empathy and suspicion describe the researcher's position, they are not value judgements. For example, the term 'suspicion' does not imply that participants are being dishonest in their account.

In adopting the hermeneutic of empathy, the aim is to understand the text from within, 'giving voice' to participants. Researchers engage with the text at a semantic level, looking for patterns across the data, rather looking for meaning that might be hidden beneath the surface. With the hermeneutic of suspicion, the aim is to look beyond the surface of the data presented for hidden meanings that might lie behind the text (Willig, 2017). In adopting a suspicious interpretation, the researcher draws on existing theory, or expertise and knowledge, to provide ideas that can be used to analyse the text beyond its surface meaning. It is not that one of these hermeneutics is of more value than the other, rather they produce different types of knowledge with the hermeneutic of empathy providing understanding and suspicion producing explanation. Although they are conflicting, Ricoeur (1970) does suggest that interpretation can be approached using both hermeneutics.

From this point of view, the interpreter is open to multiple levels of interpretation with focus on both what is said and what is not said, on both what meanings are intended and possible unintended ones.

Josselson (2004)

This is presented by Willig (2017) as a continuum, with the empathic hermeneutic at one end and the hermeneutic of suspicion at the other. Experiential approaches sit at

the empathic end of the continuum with critical approaches sitting at the suspicious end (Braun and Clarke, 2022).

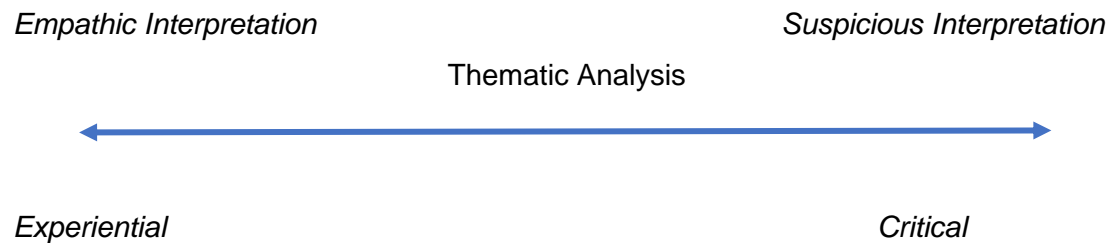


Figure 3

Thematic analysis can sit at either end of the continuum depending on the research question, approach, and use of theory, and may move between empathic and suspicious interpretation. Josselson (2004) goes on to point out that researchers must be clear about what the participant means before we can consider what meanings lie hidden.

For this study, answering the research questions required a deep understanding of the participants experience. However, the analysis needed to go beyond experience to understanding and explaining what influenced the decision to complain if that experience did not meet expectations, and what would make it easier to do so. It was possible that participants would not recognise the influencing factors and that these would only become apparent through analysis beyond the semantic level. For this study, while the orientation moved between empathic/experiential and suspicious/critical, it sat predominantly at the suspicious/ critical end of the continuum.

The Hermeneutic Circle

The main theory (and sometimes method) of hermeneutics is the *hermeneutic circle*; the meaning of a part can only be understood if it is related to the whole and the whole can only be understood if it is related to the part. However, it is not simply an accumulation of parts which equal the whole. Here Leiden University Faculty of Humanities offer a helpful illustration: while the weight of a bag of shopping (the whole) is equal to the sum of the weight of the bag plus the contents, hermeneutics is more like a recipe – the tastiness of the meal is not just the sum of the taste of the ingredients, but the blend (YouTube, 2018).

The challenging question with the hermeneutic circle is how and where does one begin; with the whole or the part? Schleiermacher (cited in Schmidt, 2006) suggests that the circle can be broken by first undertaking a preliminary reading to get an initial impression and overview of the whole, then moving back between the parts and the whole until the meaning is understood. The influence of the hermeneutic circle is evident in Chapter 5 where I outline the methods of analysis.

3.8 Conclusion

In conclusion, flowing from the research questions, a relativist ontology, constructionist epistemology and interpretive stance form the theoretical basis upon which this study is based. The theory underpinning the interpretation and analysis of data draws on Braun and Clarke's (2013, 2022) experiential and critical orientation and on the field of Hermeneutics.

CHAPTER 4: RESEARCH METHODS

4.1 Introduction

As discussed in Chapter 3, the methodological choices a researcher makes should be the ones that best answer the research questions. In this chapter, I present the case for thematic analysis and justify my decision to adopt Reflexive Thematic Analysis for this study (Braun and Clarke 2013, 2022)

4.2 Thematic Analysis

From my clinical experience thematic analysis is often cited in presentations, reports, audit and research, with authors claiming ‘the themes that emerged are...’, yet there are rarely any indications of how those themes emerged. As Braun and Clarke (2021) illustrate, many researchers fail to fully adhere to the principles of thematic analysis. If clinical practice is to be founded on robust evidence, then the methods of any research must be sound, trustworthy and ethical. As this thesis is part of a clinical doctorate programme with a focus on practice, I wanted to learn more about thematic analysis to enable me to critique this commonly cited method more effectively and to explore whether thematic analysis would offer the depth of analysis required to answer my research question.

In their seminal paper, Braun and Clarke (2006) described thematic analysis as ‘*a poorly demarcated, rarely-acknowledged, yet widely-used qualitative analytic method*’, but go on to argue that thematic analysis *offers an accessible and theoretically flexible approach to analysing qualitative data*.

Thematic analysis involves ‘*discovering, interpreting and reporting patterns and clusters of meaning within the data*’ (Ritchie *et al.*, 2014:271). While (Ryan & Bernard, 2000) describe thematic analysis as a generic tool, Braun and Clarke (2006, 2013, 2022) argue that thematic analysis should be acknowledged as a method in its own right.

Braun and Clarke (2006, 2013, 2022) state that thematic analysis is criticised for not being sophisticated enough or having the nuance, subtlety and interpretive depth for doctoral research. However, they argue that one of the strengths of thematic analysis

is that it can be applied in different ways, depending on the research question and the depth of analysis required. If applied *experientially*, it can provide a detailed descriptive account of the data but

“it can also be used to develop a critical, constructionist analysis which can identify the concepts and ideas that underpin the explicit data content, or the assumptions and meanings in the data”

(Braun and Clarke, 2013: 178)

Braun and Clarke (2006, 2013, 2022) stress the importance of being clear about the discussion of the philosophical and theoretical underpinnings of the study to ensure congruence with the choice of approach. This is important because thematic analysis is a *method* not a *methodology*. Thematic analysis does not have theory built in like Grounded Theory or Phenomenology, but it is not a-theoretical. It requires the researcher to think about all aspects of the research process and to make sound, explicit choices at all stages of the research process and reflexive applications of approaches and procedures.

How does thematic analysis fit with the epistemological and theoretical stances which underpin this study?

Thematic analysis is a method which can be used across a range of epistemological and theoretical approaches (Braun and Clarke, 2006, 2013, 2014, 2022; Braun *et al.*, 2019). For example, where qualitative researchers adopt a positivist stance (small q), thematic analysis may involve word counts used to identify patterns in texts. Elements of thematic analysis such as data reduction, also sit within a positivist frame (Bernard and Ryan, 2000).

However, thematic analysis also fits well with the constructionist/interpretivist approach of this study. Themes do not just ‘emerge’ from the data. They are not sitting in data waiting to be found - they are actively sought by the researcher through interpretation and understanding, making this a key part of the analytic process (Braun and Clarke, 2006, 2013, 2022).

4.3 Justification for the use of Reflexive Thematic Analysis.

There are many different approaches to thematic analysis. Drawing on the work of Kidder and Fine (1987) who defined small q and big Q qualitative research, Braun and Clarke (2013) describe three approaches to thematic analysis:

- i. **Coding Reliability**, (small q) whilst used to support the analysis of qualitative data has an underlying philosophy which is quantitative. The emphasis is on accurate coding through interrater reliability, measured through Cohen's Kappa. Themes and codes are inputs, often developed before analysis begins and applied by researchers who are trained in the code book and its application.
- ii. **Reflexive TA** (big Q) is a qualitative approach underpinned by a qualitative philosophy. This approach is organic and iterative. Coding is flexible and fluid with codes and themes coming from the researcher actively engaging with the data and being culturally and socially aware of their own position. It is not about accuracy and reliability, but about the researcher, through depth of engagement, conceptualising the data to tell the story.
- iii. **Code book** (bigish Q) sits on a continuum between small q and big Q. It is a more structured approach like that of Miles, Huberman and Saldana (2014) and Framework Analysis (Ritchie *et al.*, 2014). The underlying philosophy is broadly qualitative, and codes and themes can shift and change, being merged or split as the analysis progresses.

One of the most important decisions made was regarding the type of thematic analysis I would adopt. In my research proposal I identified my approach as Framework Analysis. Framework Analysis is a specific form of thematic analysis which was developed in the 1980's by social policy researchers at the National Centre for Social Research (Ritchie *et al.*, 2014). Within Framework Analysis there are two key processes- data management and data abstraction and interpretation. There are five stages to Framework Analysis:

- Stage 1 – familiarisation
- Stage 2 – developing a theoretical framework
- Stage 3 – indexing and charting
- Stage 4 – summarising data in an analytical framework
- Stage 5 – synthesising data by mapping and interpreting

What sets Framework apart from other forms of thematic analysis is the additional step of *data summary and display*. It was this element of framework that I was initially attracted to. The visual sorting of data in charts and ability to provide transparency and an audit trail was appealing.

Having its roots in applied research, with large studies and multiple researchers, Framework Analysis has traditionally adopted a pragmatic approach underpinned by a critical realist ontology and follows a largely deductive approach (Ritchie *et al.*, 2014). Knowledge from Framework Analysis can be acquired through both inductive and deductive logic, for example, the initial framework/index can be drawn directly from initial raw data (inductive), followed by the application of the framework to the remaining data (deductive) and analysis can move beyond surface description. However, the more I learned and understood about thematic analysis and the theoretical underpinnings of my research, of objectivity and 'truth', my own dual role as a nurse researcher, and the importance of reflexivity, I questioned whether this highly structured approach was the best fit for my study. Given the limited amount of literature available to guide the study, and the philosophical underpinnings, I felt adopting a more inductive approach to analysis, where codes are derived from the raw data, and may not relate directly to the specific questions asked during the interview (Nowell *et al.*, 2017), would enable a richer, deeper and more creative analysis - one where codes and themes could be developed from engagement with the data, rather than trying to fit the data into a pre-existing or researcher derived coding frame.

In addition, it is important that researchers are cognisant of their own personal ontological and epistemological leanings and their position within the research. The more I understood this, I recognised that I needed an approach that enabled me to be creative in my analysis, while embracing the reflexivity that would keep my research ethically sound. The approach to thematic analysis first proposed by Braun and Clarke (2006) and developed over the years into what is now known as Reflexive Thematic Analysis (Braun and Clarke, 2013, 2019, 2021, 2022) was more congruent with the philosophical and theoretical stances I had chosen. In a review of 19 articles (Newton *et al.*, 2012) found that reflexivity was poorly reported and often reflected a positivist stance rather than critically acknowledging the researcher's subjectivity and location within the study. I believed that Reflexive Thematic Analysis approach, sitting within a qualitative paradigm, would allow for the deep, reflexive analysis required to answer my research questions in a way that framework analysis would perhaps not.

4.4 Six phases of Reflexive Thematic Analysis (Braun and Clarke, 2013, 2022)

Phase 1: Familiarisation with the data set

This involves becoming immersed in the data. Reading and re-reading the transcripts and listening to audio recordings. At this point, brief notes are made of any analytic ideas.

Phase 2: Coding

Working through the data set, chunks of relevant or meaningful data are given labels. In reflexive thematic analysis, this can be at different levels. At a *semantic* level, the code will describe explicit meaning from the words in the text whereas at a *latent* level, the code refers to meaning that is implicit within the text.

Phase 3: Generating initial themes

Once the whole data set is coded, the next step is to identify patterns across the data set. Codes are arranged into meaningful clusters of like codes that may provide an answer to the research question. Braun and Clarke (2006; 2013; 2022) stress that themes do not simply emerge from the data.

“Theme development is an active process: themes are constructed by the researcher, based around the data, the research questions and the researcher’s knowledge and insights”.

(Braun and Clarke, 2022:35)

At this point, themes are provisional or *candidate themes*. The relevant data are then coded under each candidate theme.

Phase 4: Developing and reviewing themes

Here the candidate themes are reviewed and revised. This is done by going back to the full data set and checking that the themes make sense and are answering the research questions. During this process, there is often a radical review of candidate themes, with some being retained, or some or all being discarded. It is also the point in the analysis where the researcher begins to identify potential relationships between themes, existing knowledge and whether the themes tell a coherent story that answers the research question.

Phase 5: Refining, defining and naming themes.

In this phase the themes are refined and names that capture the essence of the theme are applied. A brief precis of each theme is written. If the refining process indicates that there is more work to do some of the analysis may still have to be 'let go' (Braun and Clarke, 2013; 2022).

Phase 6: Writing-up

Although this is set out as the last phase, the phases in thematic analysis are not linear. Braun and Clarke (2013, 2022) stress that writing-up is a fundamental part of the analysis process and not something that just happens at the end. It would often begin at phase 3 or earlier with familiarisation notes, reflexive journaling and many drafts of the final paper or thesis. Braun and Clarke (2022:176) also point out that the style of writing depends on the ontological underpinnings of the research, with those adopting a realist stance being written in the objective third person, and those adopting a relativist position written in the first person acknowledging the researcher's position in the study.

4.5 Data collection: Qualitative Interviews

Qualitative interviews are the main approach to data collection in interpretivist research (Kvale and Brinkmann, 2009). In undertaking qualitative interviews there are two key factors that require consideration; the knowledge the interviews aim to produce, and the relationship between the interviewer and interviewee.

Knowledge the interviews aim to produce

Philosophical positions can help to clarify the strengths and weaknesses of knowledge produced by qualitative research interviews. Kvale and Brinkmann (2009) describe two contrasting epistemological origins of the qualitative interview - *knowledge collection* and *knowledge construction*. They illustrate this by offering two metaphors. In the first, the interviewer is depicted as a miner who unearths the objective facts or essential meanings waiting to be found in the minds of the interviewee. The interview is separate to the later analysis of the data generated. In the second, the interviewer is portrayed as a traveller who walks with local people, encouraging them to tell their stories. When the traveller returns home and relates the stories, they are the traveller's interpretations of the narratives. The interviewer as traveller views the interview as part of the analytical process where interviewing and analysis are *intertwined phases of*

knowledge construction with an emphasis on the narrative to be told to an audience (Kvale and Brinkmann, 2009:49).

The type of knowledge sought will determine how the interviews are conducted, with those studies focussing on knowledge collection being more structured and those which require knowledge construction requiring a semi-structured or unstructured approach. Unstructured interviews are commonly used where there is little or no pre-existing knowledge, and the aim is discovery.

As discussed, for this study, the knowledge I am seeking is in the minds of the participants, but not readily available as facts to be uncovered. There is some pre-existing knowledge available to guide the interview from the literature and from my own professional and personal experience. For this reason, I adopted a semi-structured approach. A topic guide (Appendix 1) was developed as a guide to the interview which allowed participants to be free flowing in their accounts while keeping the interview focused on the research question.

The relationship between the interviewer and interviewee

In undertaking qualitative interviews, the skill of the researcher is central to obtaining the knowledge required to answer the research question. The quality of data obtained is dependent on the researcher's knowledge of the subject area, their skill in creating the right environment, and their sensitivity and timing to ask follow-up questions (Kvale and Brinkmann, 2009).

The relationship between the interviewer and the interviewee is not always equal with the researcher often seen as the professional expert, sometimes from a higher socio-economic group from participants. It is often a one-way conversation with the researcher directing the questions according to the research question, and the interviewee seen as the lay person who answers (Coar and Sim, 2016; Kvale and Brinkmann, 2009). It is therefore incumbent upon the researcher to do everything possible to minimise the power asymmetry and engender mutual trust and respect. However, when the researcher is a clinician interviewing other clinicians, there is an additional layer of complexity. I consider this further in Section 4.9 when I discuss reflexivity and my position within the study.

As an *insider* researcher, a nurse interviewing other nurses, relationships can range from close friends to unknown fellow professionals (Quinney, Dwyer and Chapman,

2016). Establishing a relationship built on trust between the interviewer and interviewee is essential, not just to facilitate an open honest dialogue, but to ensure there is no harm to either party during the interview. As a senior nurse and researcher, I did not want my professional position to influence the way participants felt about being open and relaxed in the interview. Self-disclosure can help to build a connection with participants (Wood et al., 2019). I began each interview by sharing some of my own experience and explaining my motivation for undertaking the study.

Due to the sensitive nature of the subject all participants were interviewed face to face rather than by telephone. Interviews were arranged at a time and venue that suited the participants. This ranged from some people preferring to be interviewed in their home, others their place of work and a few preferred to come to my office building. Quinney *et al.*, (2016) highlight that the choice of location when interviewing peers can shift the power dynamic from the researcher to the participant and vice versa. Conscious of the potential increased power imbalance for those who chose to come to my office, I booked a quiet, comfortable meeting room away from the main office. Quinney, *et al.* (2016) also suggest that the balance of power can shift to participants. For example, the researcher may be knowledgeable, but may be out of their comfort zone conducting interviews in the participants workplace where the interviewee is seen as expert. Through the post interview reflexive accounts, I recognised that I did feel more nervous going to interview in an unfamiliar location such as someone's home. However, I found that opening with self-disclosure and the motivation for the study also allowed me time to relax into the interview. I was fortunate to come to this study with the experience of having undertaken interviews many times and in different contexts as part of my professional role. However, undertaking interviews as part of my own research was new. I decided that to enhance the quality of the study I would undertake two pilot interviews. I discuss these in Section 4.9.

4.6 Sampling

Sampling is necessary in most types of research as it is rarely possible (or desirable in qualitative studies) to carry out a census that includes data from a whole population (Gerrish and Lacey, 2010). There are two types of sampling; **probability sampling** which is used in quantitative studies where the sample is representative of a known population and therefore results from data analysis can be generalised to the whole population, and **non-probability sampling** used in qualitative studies where the aim

is not to generalise findings, but to provide rich information and understanding that may be of interest and applicable in other settings (Gerrish and Lacey 2010, Robson 2011).

For qualitative research to be trustworthy, the sampling strategy needs to be transparent, and the choices made must fit with the aims, the questions and the underlying philosophical assumptions of the research (Braun and Clarke, 2006, 2013, 2022). In addition, researchers also need to consider pragmatic issues such as the time available, cost and accessibility of potential participants.

The main approaches to non-probability sampling are quota sampling, purposive sampling and convenience sampling. In qualitative research, researchers may use a combination of sampling techniques (Gill, 2020).

Quota In quota sampling, the researcher identifies a given number of the population representatives under each category of interest. Within each category, convenience sampling (see below) is usually used to reach the quota. Robson (2011) warns that care is required in the use of the term 'representative' as participants are representative in number only – not in the type of person selected.

Convenience Common in large surveys, convenience sampling involves selecting the most convenient and accessible people to be part of the study. While it can be used in initial piloting to get a sense of pertinent issues, it is recognised as the least rigorous sampling strategy (Robson 2011).

Purposive Here the sample is intentionally sought out by the researcher to fulfil the requirements of the study. This is different from convenience sampling as the researcher uses judgement and expertise to select participants who are knowledgeable about the phenomenon being studied (Gill, 2020).

Snowball In snowball sampling, having identified one or more people to participate in the study, participants are asked if they know of anyone who fit the inclusion criteria that may be willing to take part in the study. This can be useful when the population is difficult to reach (Gerrish and Lacey 2010, Robson 2011)

Justification of sampling strategy

In this section I explain the rationale for my sampling strategy outlining why the original plan changed from quota sampling to a more organic strategy that involved purposive and snowball techniques.

The target population

The first step in determining the sampling strategy is defining the population from which the sample will be drawn. Drawing the sample from all nurses in NHS Scotland who had been patients or relatives of patients and had a poor experience of care would not have been feasible. Pragmatically, as a sole researcher undertaking the clinical doctorate programme on a part time basis while working full time, I limited recruitment to NHS Boards within a 50-mile radius of Lothian to enable me to meet participants for face to face interviews. The target population for this study was 'nurses who have been patients or relatives who have experienced (directly or witnessed) care or treatment which they perceive to have been poor and who live within a 50-mile radius of Lothian'.

Deciding the sampling technique

In my research proposal I had intended to use quota sampling as I had thought having equal numbers in each category would enable me to compare the reasons for complaining, raising concerns or neither complaining or raising concerns and compare the any differences between nurse patients and nurse relatives.

Quota sampling would have fitted with using Framework Analysis (bigish Q), where the logic is more deductive, and a framework of codes is developed early then applied to the data. However, having decided that I would adopt Reflexive Thematic Analysis, the decisions I made regarding sampling needed to fit with the interpretive, constructivist, theoretical underpinnings of my study.

Quota sampling is usually derived from a known sampling frame (such as the electoral register or telephone directory) or a researcher derived sampling frame from which the smaller sample(s) are drawn. The other reason for rejecting quota sampling was that there was no readily available sampling frame for this study. The population of interest were not readily known or available. This was made more challenging as my original plan to approach potential participants through NHS Board complaints teams was rejected by the ethics committee. However, the ethics committee made helpful suggestions as to how I might advertise my study through posters in clinical areas, the

Royal College of nursing and social media. I therefore decided to use purposive sampling and snowball sampling.

The next step was to clearly identify the categories of people and experience I would need to answer the research questions. Setting the following inclusion and exclusion criteria provided parameters around the sample while focusing recruitment on people with the range of experience to provide the depth and richness of data required.

Inclusion and exclusion criteria

Inclusion Criteria

Registered nurses who have been a patient who have either;

- made a complaint themselves about care or treatment they have received,
- made a complaint through a third party (this is where, for example, a relative or MSP writes on the patient's behalf), about care or treatment.
- raised concerns locally about the care they have received
- experienced care which they perceive to be poor, but have chosen not to complain

Registered nurses who have had a relative who has been a patient and who have witnessed that relative receiving poor care and either;

- made a complaint
- made a complaint through a third party about care or treatment their relative received
- raised concerns locally about the care their relative received
- chosen not to complain.

Exclusion Criteria

Registered nurses who have not had the experience of being a patient or relative of a patient who has received poor care.

Registered nurses who live out-with a 50-mile radius of Lothian.

Sample size

Sample size in qualitative research is the subject of much debate within contemporary research methods literature, with one of the main arguments being whether it is possible to pre-determine the sample size (Blaikie, 2007). The following section

outlines the issues I considered and decisions I made in determining the sample size for my study.

Borrowing from quantitative methodology, DePaulo (2000) and Guest, Bunce and Johnson (2006) argue that a qualitative sample can be calculated through statistical processes. For DePaulo (2000), the objective of determining sample size should be to minimise *discovery failure*, the chances that a significant perception might be missed. Guest *et al.* (2006) highlight the importance of predetermining sample size, particularly in applied research where the research is dependent on securing funding and resource. Guest *et al.* (2006) conducted an experiment to quantify the number of interviews required to reach saturation. The experiment was undertaken using codebook thematic analysis. Intercoder reliability was assessed using Kappa scores and interviews were highly structured. Pre-determining sample size through statistical approaches may be appropriate for highly structured qualitative studies, but as Guest *et al.* (2006) acknowledge, this approach is not suited to inductive, iterative approaches.

Sampling for Reflexive Thematic Analysis

The point at which the sample size is decided – either *a priori* or once data collection and analysis are complete depends on the ontological and epistemological assumptions made.

As discussed, in some forms of thematic analysis such as codebook analysis, a realist or critical realist ontology underpins the methods. Epistemologically, such studies follow a largely deductive approach, where codes and/or themes are identified in advance then applied to the data; the underlying assumption being that meaning can be ‘*excavated*’ from the data (Braun & Clarke, 2021).

In reflexive thematic analysis, themes are constructed and developed from codes that can be semantic but are often latent – implicit within the text. As previously discussed, themes come from interpretation and analysis – they are not waiting to be found (Braun and Clarke, 2006; 2013; 2021). The underlying assumption in reflexive thematic analysis is that

'..meaning is not inherent or self-evident in data, that meaning resides at the intersection of the data and the researcher's contextual and theoretically embedded interpretive practice.'

(Braun and Clarke, 2021)

As themes are developed late in the analytical process, it is difficult to determine the size of the required sample at the outset.

How then does the researcher know when to stop collecting data?

One of the most cited methods for determining sample size in qualitative research is *saturation*. Yet, as many commentators point out, there is no universal understanding of what saturation means and how it is achieved is often poorly explained within research papers (Low, 2019; Nelson, 2017; Saunders et al., 2018). *Theoretical saturation* originated in Grounded Theory (Glaser and Strauss, 1967) but is now used more widely across qualitative research where it is referred to as *data* or *thematic saturation*.

Data or thematic saturation generally refers to the point where no new additional codes or themes can be found in the data therefore data collection can stop. While saturation is cited by some as the gold standard for determining sample size in qualitative research (Fusch & Ness, 2015; Guest et al., 2006), for others it remains problematic because of variation in the definition and process (Felix Chukwuma Aguboshim, 2021; Nelson, 2017) how it should be conceptualised (Saunders et al., 2018); and whether it fits with the underlying philosophical assumptions in the research (Braun and Clarke, 2021; Saunders et al., 2018). Low (2019), giving the example of re-analysis of data, argues the notion that 'no new information' in data analysis is 'logical fallacy' as 'Analysis is never complete; there is always something new to discover, some new insight to be made'. (Low, 2019:131)

Using the concept of data saturation to determine the size of my sample appeared to be at odds with the underpinning philosophical stance of this study. I was therefore left with the problem of how to assure the rigour of my sampling strategy and how to know when I had collected enough data.

Pragmatic considerations

While predetermining the sample size and data saturation may be at odds with the philosophical underpinnings of Reflexive Thematic Analysis, Braun and Clarke (2021)

acknowledge that there may be pragmatic reasons why it is necessary to give some indication, such as planning workload, committing resources, demands of ethics committees or university programme requirements.

According to Mason (2002) the key question regarding sample size is to ask whether the sample provides enough data with the right focus to answer the research question. For example, studies may require a larger sample where less in-depth and 'shallow' the data are captured. By contrast, those where data is richer may require fewer participants.

Pragmatic ways of pre-determining sample size include *rule of thumb*: using previous research experience, and looking at previous, similar studies. Using supervision, I was able to draw on the knowledge of experienced researchers. In addition, I reviewed the richness and depth of data from the pilot interviews. I aimed to recruit a sample of around 10 to 15 participants.

4.7 Recruitment

Mason (2002) points out that access to participants is not always straightforward and may have to be negotiated with ethics committees, organisations and gatekeepers. Even when permission has been given, there is no guarantee that people will want to take part in the study.

I was advised by the Ethics Committee that I should not ask complaints teams to approach complainants on my behalf as they had concerns about confidentiality. Instead, it was suggested that I should recruit through advertising my study through the Royal College of Nursing, Patient Opinion, NHS Boards, in addition to snowball sampling.

I approached the Research and Development Departments in 5 NHS Boards to ask if I could advertise my study. While four were supportive, one refused permission on the grounds that they felt there was a conflict of interest with my (then) role as Deputy Director of Scrutiny. Although permission was declined to advertise the study, nurses working in that NHS Board could still have replied to the RCN or Patient Opinion advert. However, the refusal to allow me access led me wonder about the culture of openness in NHS Boards and whether that would influence potential participants' decisions to take part in the study.

While waiting for approval from the NHS Boards, I advertised the study through the Royal College of Nursing and Patient (now Care) Opinion (appendix 2). Within the first two weeks I had recruited five participants. Feeling a bit overwhelmed at how quickly people had responded, I decided at that point to pause and not proceed to advertising in the NHS Boards. This was for two main reasons. Firstly, I needed to keep the workload manageable. Secondly, I wanted to review the data from these initial interviews to get a sense of whether the data was of the right breadth and depth and rich enough answering my research questions as this would influence my sampling strategy. The use of supervision was pivotal throughout this process, allowing time for challenge, discussion, reflection and stocktaking.

As most of the participants interviewed said that they knew of nurses who had been in a similar position therefore I was less worried about the ability to recruit to the study. Participants indicated that they were interested in taking part in the research by responding to the email address provided in the advert. On receipt of the email, a participant information sheet (Appendix 3) was sent for consideration with a consent form to be returned.

The table below shows how the final sample of 12 participants were recruited to the study.

Table 5: How the final sample were recruited

Participant Number	How recruited
01 and 02 (pilot interviews)	Participants had heard that I was advertising the study and approached me to ask if they could participate
03 - 06	Responded to RCN advertisement
07	Snowball – recommended by participant
08	Recommended by a work colleague
09 and 10	Responded to RCN advert (cascaded through work email)
11	Snowball – recommended by a participant
12	Heard about the study word of mouth and volunteered

Introducing the participants

The following table gives a brief overview of the participants.

Table 6

No.	Pseudonym	Length of time qualified	Specialty (for most of career)	Patient/relative	Setting of experience	In own place of work?
01	Gemma	>10 years	Dermatology	Relative – patient was her mother	Primary care	No
02	John	>10 years	Medicine of Elderly	Relative – patient was his mother-in law	Hospital - care of elderly	No
03	Joan	>20 years	Education	Relative – patient was her father	Hospital Acute	No
04	James	>5 years	Education	Relative – patient was his wife	Hospital clinic	No
05	Shirley	>20 years	Research Clinical Nurse	Patient	Hospital clinic & primary care	No
06	Gillian	>20 years	Research	Relative – partner was the patient	Hospital Acute	No
07	Julie	>20 years	Hospital Clinical Management	Patient	Hospital Acute	Yes
08	Jennifer	>20 years	District Nurse	Patient	Hospital Acute	No
09	Pat	>20	Education	Both patient AND relative to her sister, brother and mother-in-law	All experiences in Hospital Acute	No
10	Samantha	<5	Surgical Nurse	Relative – patient was her mum	Hospital surgery	No
11	April	>20	Orthopaedic Nurse	Relative – Patient was her Mother-i-Law	Hospital Medicine of Elderly	No
12	Susan	>20	Hospital Clinical Management	Relative- Patient was her son	Hospital Acute	Yes

As illustrated, 2 participants were male and 10 were female. The majority had been qualified over 20 years with 2 participants being qualified over 10 years, one over five years, and one just under 5 years. Five participants worked in either research or education. This could be related to the method of advertisement and participants that would most likely read the RCN bulletin. Three participants told of their experience of having been a patient, and 8 of having been a relative. Pat wanted to tell the stories of her experience as both a patient and as a relative. Two participants; Julie who was a patient, and Susan who's relative was her son, described their experiences as being in the hospital in which they were also employed.

4.8 Ethical considerations

Prior to undertaking the study, ethical approval was sought and obtained from The University of Stirling NHIS, Invasive or Clinical Research (NICR) Ethics Committee and NHS East of Scotland Research Ethics Committees. An annual report was submitted to NHS East of Scotland Ethics Committee, and this included updating the committee on the revision to my sampling strategy. The fluidity and nature of qualitative research means that ethical issues need to be considered throughout the research process (Braun and Clarke 2013). The following sections outline my key considerations.

Consent and confidentiality

Consent to participate in the study was obtained in writing (signed and dated) and again verbally prior to the interviews taking place. Consent was also obtained to record the interview and to outsource the recording to a third party within the UK for transcription. Participants were informed that they could withdraw consent at any time during the study.

Each participant was allocated a number and transcriptions were anonymised using the number rather than the participants name. This number was used to identify participants throughout the process of data coding, sorting, and analysis. Pseudonyms were used in writing up the findings. Although I captured a limited amount of demographic data from participants, such as gender, age, years qualified and specialty, this is presented in **Table 6** at a high level to further reduce the risk of participants being identified.

Data Management

Data collected for the study was managed in line with Stirling University *Data Protection Guidance Handbook* (2017). Personal data collected was kept to the minimum required for the study; participant email address, name, length of time qualified, area of clinical practice.

As a part time student, my doctoral work was undertaken in my office at home. The office is always locked and has a security alarm. It is only accessed by me. Signed copies of the consent form, the digital recorder, and hard copies of anonymised interview transcripts were stored securely in a locked cupboard within the office.

Participant and researcher safety

Given the sensitive nature of my research, in addition to considering physical safety I also considered the emotional and psychological safety of the participants and myself as the researcher.

Given the participants were registered nurses, I deemed the risk of physical harm to be less than that of other populations. However, when interviewing participants in their own homes, particularly in the evening I did consider the fact that I did not know people's social circumstances. There were also times when I would be driving in the dark during winter months. To mitigate the risk, without disclosing participant details, I phoned my partner on arrival and on completion of the interviews.

I was aware that talking about traumatic events could be potentially harmful to participants. For this reason, I ended each interview conversationally by asking participants what they would be doing following the interview. I also included where participants could access counselling services as part of the participant information sheet. In reality, many participants commented that although they had been upset during the interview, they felt that being part of the study had helped them as they thought that having told their story it might make a difference. This highlighted another important ethical issue- having interviewed the participants, I had a duty to publish my findings.

Having worked in complaints management, I was also aware of how distressing it can be to listen to and absorb difficult and emotional information in terms of my own emotional wellbeing. This was a challenge when, because of their distance from my home and proximity to each other, I interviewed two of my first participants on one day. Feeling completely drained, for subsequent interviews I made the decision to only undertake a maximum of one interview in a day.

4.9 Quality and trustworthiness in qualitative research

Another important ethical issue is providing assurance that the research is trustworthy. As there is no one single way to undertake qualitative research, methods for ensuring validity rigor, credibility and trustworthiness of the research and findings will vary according to the underlying paradigms and epistemologies.

In this section I outline the four strategies I adopted to enhance the quality and trustworthiness of my research.

1. Reflexivity
2. Supervision
3. Audit Trail
4. Pilot Interviews

Reflexivity

Working in a health culture where randomised controlled trials are still seen in some quarters as the gold standard for evidence, and objectivity and the elimination of bias are core to research, one of the first challenges in undertaking qualitative research was understanding that subjectivity is not only acceptable within qualitative research, but an essential part, particularly in Reflexive Thematic Analysis.

“Your subjectivity is essential to the process of reflexive TA; it is the fuel that drives the engine and reflexive TA doesn’t happen without it”

(Braun and Clarke, 2022 p12)

Aligned to subjectivity is the practice of reflexivity. Whitaker and Atkinson (2021) are critical of the way reflexivity is often presented in research papers as a ritualistic part of the methods section, driven by the expectation of examiners, that focuses on personal and inter-relationship issues rather than being an integral part of the whole research process.

There is no one definition of, or approach to, reflexivity. Reflexivity is a challenging process that goes beyond simple self-reflection, to the researcher critically analysing their own political and personal values; their relationship with participants; their situation in and relationship with the research; the methodological choices adopted; and the wider cultural and environmental context in which the research is taking place, and how all these factors influence the analysis of the research and production of knowledge. (Dean, 2017; Finlay and Gough, 2003; Wilkinson, 1988; Ibrahim and Edgley, 2015)

Finlay (2002) identified five variants of reflexivity

Introspection the researcher draws on their own experience as primary data to make sense of the emotional and social worlds of participants.

- Intersubjective* the focus is on the nature of the research encounter and the relationship between the researcher and the participant. Researchers explore the mutual meanings within the research relationship.
- Mutual collaboration* used in a wide range of participatory methodologies where participants are viewed as reflexive co-researchers.
- Social critique* reflexivity is focused on the power imbalance between the researcher and participants, for example, in class, gender and race.
- Ironic deconstruction* this form of reflexivity focuses on meanings embedded in language. – there is no one authoritative voice. Multiple interpretations are possible and contradiction is embraced.

Finlay (2002) points out that each variant of reflexivity is not without its critique and suggests, for example, that without critical analysis, introspection and intersubjective reflections could be viewed as self-indulgent. Finlay (2002) goes on to say taking reflexivity as a whole, the important part is that it is done well and that researchers should adopt the style of reflexivity that suits the values and methodology of the research, drawing on a number of the variants if required. In her discussion of the role of reflexivity in feminist psychology, Wilkinson (1988) identified three forms of interrelated reflexivity; *personal, functional and disciplinary*, with 'personal' and 'functional' being closely intertwined.

Personal reflexivity refers to the researcher as a person and how personal aspects of their life, such gender, culture, occupation family circumstances, interests, values and beliefs might influence their research. Functional reflexivity refers to the form of the research and the various choices researchers make. The reason Wilkinson (1989) describes personal and functional reflexivity as inseparable is that the choices made regarding the subject for the research are usually rooted in personal interest, and decisions about methodology and during analysis and are shaped by personal values and circumstances. Functional reflexivity also requires examination of the relationship between the researcher and participants and the acknowledgement of potential power imbalance in the construction of knowledge (Wilkinson, 1988).

The third form of reflexivity described by Wilkinson (1988) is disciplinary reflexivity. Disciplinary reflexivity goes beyond that of the individual, personal reflexivity and of functional, methodological reflexivity to a more collective thought and considers how the wider academic disciplines, including different paradigms, academic institutions and countries influence research. For example, the influences of feminist, queer and Indigenous research approaches create conditions where traditional power balances within research are challenged (Braun and Clarke, 2022; Whitaker and Atkinson, 2021; Wilkinson 1988).

My Approach to Reflexivity

For this study, I focussed mainly on the areas of personal and methodological reflexivity. The most important tool was the reflexive journal kept throughout the duration of the research. Often this took the form of a notebook kept for the purpose, but often it meant jotting down scrap paper or recording thoughts on my phone if ideas occurred to me when out riding or walking. The journaling felt awkward at first as it was not something I was used to. However, it soon became invaluable, particularly when I was trying to get to grips with some of the theory and methodological choices. It became even more important during the interviews with participants and essential during the analysis. Evidence of my reflexive practice is woven throughout my thesis as I explain the methodological choices made and approach to analysis. However, the journey into reflexivity began by considering my own position within the study.

Personal Reflexivity: My position within the study

An important epistemological issue is the relationship between the researcher and the researched (Blaikie, 2007; Ritchie *et al.*, 2014). In acquiring knowledge, the researcher must choose the kind of relationship he or she will have with research participants. Part of this choice rests on whether the researcher believes it is possible or desirable to be truly objective and where the researcher is situated within the study. Blaikie (2007) describes the researcher's position along a continuum between two extreme positions: *outsider or insider*. Between these polarities are a range of stances. As an outsider, the researcher stands back from the phenomenon being studied and uses methods that allow the researcher to observe, maintaining a 'professional distance' from the research participants. As an insider, the researcher becomes immersed in the social world of those being researched, often becoming part of the community or group, as would be the case in field research and ethnography. However, Corbin-Dwyer and Buckle (2009) argue that the issue of researcher membership in the group being studied is relevant to all qualitative research as the researcher plays "*a direct and*

intimate role in both data collection and analysis". They go on to argue that while there are advantages and disadvantages to insider/outsider status, the important factor is not the status per se, but

"..an ability to be open, honest, deeply interested in one's research participants, and committed to accurately and adequately representing their experience".

Corbin-Dwyer and Buckle (2009 p58)

The position of the researcher begins with what motivated them to undertake the study, followed by the research question, the methodological choices made, and through to the analysis and findings. As circumstances change throughout the lifetime of a study, the degree to which the researcher is situated inside or outside may shift. What is important is that the researcher recognises and explains their position and how they have addressed any of the disadvantages.

As a nurse studying nurses, I am an insider. I am part of a nursing community that shares language, customs and practice.

I am also the daughter of a mum who lived in a nursing home and during the time of my study there were times where the care she received fell below the standard I would have wished her to have. She had advanced Alzheimer's Disease and during the time of my research she sadly died. This experience put me further into the position of 'insider'. Not only was I a nurse, but I was also a nurse relative who had witnessed poor care and had experienced a bereavement.

I then had the experience of being a patient following a broken collarbone which required a surgical repair. Although the care I received was excellent, the complex recovery and impact on my life was not, and resulted in me having to take a year's leave of absence from my research. I could certainly resonate with the feelings of vulnerability and desire to be a 'good patient'.

In addition, I have extensive experience in managing complaints. From my awareness of policy, literature and theory surrounding patient experience and complaints, and from experience of working with staff, patients and relatives, I have doubtless formed my own assumptions about the subject, some of which I recognise I may not be fully conscious of.

Being an insider can have advantages, for example, accessing potential participants and recruiting to the study, people feel relaxed and can be more open during interviews. However, there are disadvantages. As Breen (2007) highlights, familiarity can lead the researcher to make assumptions based on their prior knowledge and experience and they can have difficulty balancing their insider role (in my case being a nurse) with the role of researcher. In addition, Quinney *et al.* (2016) point out that there are situations such as if participants become upset during the interview that the nurse researcher is at risk of moving into a nursing rather than researcher role and respond to the situation as a healthcare professional or as a nurse counsellor.

Adopting a position towards the insider end of the continuum is compatible with the epistemological underpinnings of my study. In adopting a social constructionist approach, I am not seeking to be objective, I am seeking to interpret and construct meaning from the experiences of the nurses participating in the study. However, I recognised that for my research to be credible, I would need to demonstrate that I had adopted robust processes to assure the quality of the study and to ensure that the research was ethically sound.

One other factor that I had to consider is the different jobs I have held during the course of my study, I have changed jobs twice since beginning my research and have had to consider how these different positions could (and have been) be perceived as conflicting with my role as a researcher. This was brought starkly to light when I was refused R&D approval to advertise my study by one NHS Board who believed that my role within Healthcare Improvement Scotland, where I led various healthcare inspection programmes, was a conflict with my research. I had been clear that Healthcare Improvement Scotland do not investigate complaints from individuals; that is a matter for the NHS Board and the Scottish Public Services Ombudsman. As I discuss in Section 4.8, the NHS East of Scotland Research Ethics Committee had suggested that in addition to advertising in NHS Boards, I advertise through the Royal College of Nursing so nurses from that NHS Board could have participated in the study through another route. Although disappointing, it prompted me to reiterate prior to any interviews that my role was as a researcher and that any information shared would not inform any of the inspection programmes.

Supervision

As a novice researcher, one of the most important quality control measures was the effective use of supervision throughout the research process. This was particularly so

when getting to grips with the complex theoretical and methodological choices and through the various iterations of analysis.

Audit trail

Keeping a clear audit trail is another important feature of producing high quality qualitative research (Braun and Clarke, 2022) This took on a number of forms including, reflexive journaling, data charts (some borrowed from Ritchie et al.'s (2014) Framework Analysis), and notes from supervision sessions. Having had to take two separate year-long episodes of leave of absence during the course of my research, having a clear audit trail meant I could quickly re-engage with my research while having the advantage of fresh eyes.

Pilot interviews

Although more common in quantitative and large-scale studies, pilot studies can be useful in qualitative research, particularly for novice researchers (Doody & Doody, 2015; Ismail *et al.*, 2017). Conducting a pilot study enables the researcher to assess potential issues with recruitment, test data collection instruments, identify any methodological issues and evaluate their data analysis method. However, it is also argued that as the nature of qualitative interviews are often progressive, with interviews being refined as the research progresses, pilot studies are not required. (Doody and Doody 2015, Ismail *et al.*, 2017)

As a novice researcher, I felt it was important to assess the quality of my work at this point, as any flaws would have significant impact on the quality of data, analysis and findings. While the size of my research project did not warrant a full pilot study, I decided to undertake two pilot interviews. The purpose of this was to test the semi-structured interview schedule, practice and obtain feedback on my interview technique, and to practice coding the data I collected from the interviews.

Recruitment

As described, my recruitment strategy was through advertising and snowball sampling. Two colleagues who had heard me talking about my study had approached me and shared that they had experience that they thought would fit with my study. As discussed, the relationship between the interviewer and the interviewee is central and interviewing peers and people that are known to the researcher brings important methodological and ethical implications (Coar and Sim, 2006). I had to consider in

what way my knowing the participants may influence the way participants would respond and how this would affect my data. Would the participants be more open because they knew me? Or, would they be more guarded about disclosing personal information to a work colleague?

As both participants had approached me in the first instance, I believed they felt comfortable about me interviewing them. I therefore gave them the participant information and obtained their signed consent. I explained that I was conducting two pilot interviews and that depending on the evaluation of my interview schedule and interview technique the data may not be used in the final study. Both participants were happy to proceed.

Immediately prior to the interviews, I again checked that they understood the participant information and that they were still content to be interviewed. I offered to conduct the interview in a place that the participant felt most comfortable. As the participants had access to meeting rooms, they requested that the interviews were held in their place of work.

Following each interview, I listened to the recording and wrote a reflexive account. This outlined areas where I thought the interview had gone well and where I felt my technique could be improved. I also noted points of interest that initially occurred to me.

Box 1 below contains an extract from my reflexive account following the first interview.

Box: 1**Extracts from reflexive account interview 01**

In the initial part of the interview 01 told the story of her mum. I can hear that during the story I was making empathic sounds and sounds of encouragement.

During the story I noticed that 01 described being very assertive with the GP and this came over in her voice. She was almost threatening when she described how she told the GP she would use her position in the health board to speak to the Chief Exec.

I noticed that she used her position and knowing how the system works to get her mum admitted to hospital. She also used her nursing knowledge to assess her mum's clinical condition and knew that the issue was serious. Describes having the professional confidence that working in the NHS Board gave her to challenge as much as the nursing knowledge

During the interview, I liked the way I followed up answers with '*can you tell me a bit more about that?*'

However, at one point I said '*You obviously felt*' – I shouldn't have said obviously. I will try to frame as a question next time eg *Did you feel that...?*

Just before the meeting started and off recording, 01 told me she had a meeting to attend following the interview. I asked if she wanted to reschedule but she was keen to continue. If I'm honest I was relieved as I had psyched myself up for the 1st one! Although I have extensive experience of interviewing people in different settings, and often people I know well, this was my research and, as a novice researcher, I hadn't anticipated how exposed I would feel interviewing people I know.

Towards the end of the interview, it was time for the participant to attend her meeting. The recording was stopped fairly abruptly, and I had trouble with the recorder switching off and on.

Throughout the interview, I didn't refer rigidly to the schedule and was able to let the conversation flow, but because of this I was concerned that the information was not going to answer the question. It's not on the recording but I spent the last few minutes checking through the Interview Schedule (panicking a bit) and still needed to ask about what would make it easier to complain. We agreed to meet up the following day to complete.

I learned that sometimes the interviews won't go exactly as planned. I would be prepared for example if the recorder failed to have to take notes.

I asked 01 to reflect on yesterday's interview - how she had felt and if there was anything I could do to improve. She said that she had felt I had a nice warm approach and that I had put her at ease. I was pleased as I thought the interview had gone well.

Listening to the recordings, I was surprised at how little I spoke. The participants were keen to tell their story, and they were naturally covering the questions in my schedule. It is important to find the balance between allowing the participant to lead, uncovering themes not previously considered by the researcher, and answering the research questions (Kvale and Brinkmann, 2009). I was initially concerned that the focus of the interview was heavily weighted towards the participant's experience rather than the answers to my research question. I was aware of this during the interviews, but I found that I could not interrupt their story telling as it clearly mattered and at times was very emotional. Indeed, one of the participants told me that the reason she wanted to take part in the study was because she had not complained about her experience at the time and she felt that taking part in the study would in some way make a difference.

I discussed my reflexive accounts with my supervisors. Having listened to each of the interviews they gave me positive feedback, stating that I had a relaxed interview style and that I put the participants at ease. They pointed out a couple of occasions where I was asking slightly leading questions and I was able to reflect on how I could improve this in future interviews.

We also discussed my concern that while the participants stories of their experience were important, I needed to answer my research questions. They agreed that interrupting their stories would not have been appropriate. They suggested that I should explain to participants at the beginning of the interview, that while I was interested in hearing their story, the focus of my research was to find out the reasons behind their decision to complain or not and that I might have to bring them back to the question. I did this for future interviews.

Having received feedback on my interview technique, the next step was to undertake preliminary analysis of the data from the interviews.

Phase 1: Familiarisation

The first phase of thematic analysis is familiarisation – becoming immersed in the data. I began this process by listening to the interview recordings several times. For many researchers, a key part of familiarisation occurs during the transcription of audio data. As I don't touch type, I made the decision to outsource the transcription of my interviews to a company used by the university. I asked for the transcripts to be verbatim and to include all words, pauses and sounds. The quality of the transcript is

important, as if punctuated incorrectly, the meaning of a data section may be lost or changed, directly impacting on the quality of future analysis.

I began the process of immersing myself in the interview data by listening to the recordings several times while reading the transcripts. In doing so, I was able to add in text where the transcriber had not understood a word and left a gap. I then began to note areas that I thought were interesting on the margins of the transcripts.

Phase 2: Coding

Now familiar with the data and having some idea of the broad issues the two participants were talking about, the next step was to begin to code the data. To support my learning and aid discussion, my supervisors also coded the data from the pilot interviews. The subject of inter-rater reliability is sometimes raised when considering approaches to coding in qualitative research: would two researchers code the data in the same or a similar way? (Braun and Clark, 2013) However, in qualitative research, while some consistency may be required where there are teams of researchers, the aim is not to produce a replicable set of codes, but to answer the research question in a transparent and systematic way that enables the reader to see how concepts and themes were developed (Ritchie *et al.*, 2014:278).

Braun and Clarke (2013) describe the researcher's role in the analysis of qualitative data as that of a sculptor: no two sculptors will produce identical sculptures. The purpose of my supervisors coding the data was to give a different perspective and facilitate discussion as to how we had arrived at selecting particular codes. This was hugely helpful in building my confidence as we had all coded the data in a similar way.

Complete coding involves working throughout the whole data item [in this case interview transcripts] looking for chunks of text which may be relevant to the research question (Braun and Clarke, 2013; 2022). Working in the margin of the hard copy I named sections of text ranging from a few words to a few sentences. Codes can either be data-derived or researcher-derived (Braun and Clarke 2013; 2022). Data-derived codes are a concise summary of a section of data and closely reflect the participants words. Researcher-derived codes label *implicit* meanings within the text.

In naming and applying a code I continually asked the question '*what is being said here?*'. The following extract in **Table 7** is from my notes on coding the transcript of Gemma's (P1) interview.

Table 7

Transcript Extract	What is being said here?
<p>I think she wouldn't have got a bed if I hadn't been working in the health board, if I hadn't had that level of understanding. I may not, I noticed the oedema on her abdomen and was able to flag that up. If I didn't know how to spot that oedema even the cyanosis, you know around the lips and I wouldn't necessarily have understood the significance so I maybe wouldn't have made so many phone calls, so I think me being a nurse did have an impact on the doctor's reaction, and even access into primary care and then the acute effect in terms of getting her into [hospital]. Gemma (P1)</p>	<p>Here, Gemma was using her nursing knowledge to assess her mum. The language she used was technical and she was speaking as a nurse.</p> <p>What she says goes beyond her technical nursing knowledge to her knowledge of the system</p> <p>She was taking charge and using her position to get her mother admitted to hospital. During the interview she almost sounded aggressive when she was describing how she influenced the GP.</p> <p>Codes :</p> <ul style="list-style-type: none"> • Using nursing knowledge • Knowing the system • Balance of power

During this process, I found that my earlier concerns about not answering my research questions were largely unfounded. The data I needed to answer the question was there – it was just not neatly packaged. As the interviews were giving me the data I needed, I did not make any amendments to the interview schedule.

Another consideration in undertaking the pilot interviews was whether I could include the data in my study. As there were no changes to the interview schedule and minor improvements to my interview technique, I decided that I could safely incorporate the data into the main study. The next step was to complete my data collection by undertaking a further 10 semi-structured interviews.

4.10 Conclusion

In conclusion, Reflexive Thematic Analysis was chosen as a method congruent with the theoretical underpinnings of the study. The sampling strategy included purposive and snowball sampling. Data were collected through a semi-structured interview with each participant following informed consent.

Significant consideration was given to the quality and trustworthiness of the research with reflexivity and my position, holding multiple roles being fundamental. In addition,

effective use of supervision, a clear audit trail and undertaking pilot interviews enhanced the trustworthiness and credibility of the study.

CHAPTER 5: ANALYSIS

5.1 Introduction

In this chapter, I describe my approach to data analysis and explain the processes I followed to construct the final themes. Analysis in qualitative research is not linear; it is a complex process that involves going back and forth from codes and portions of data to data items, (in this case interviews and transcripts) to the whole data set.

5.2 Phase 1: Familiarisation

The first step in analysis was to immerse myself in the whole data set. As with the pilot interviews, I had outsourced the transcription, therefore checking the accuracy of the transcripts was a vital part of this process. The following example illustrates where the transcriber had misheard part of a sentence: “... *you might just have a bit of a, you need perspective.*” Should have read ‘*you might have a bit of a unique perspective*’ (Joan, P3). Here the participant is talking about the unique perspective that being a nurse gave her while her father was in hospital. This is important as it gets to the heart of the research question. It could have been overlooked had I not been rigorous in checking the transcripts whilst listening to the recording.

I read and re-read the transcripts many times until I had a good understanding of the type of issues participants were talking about. Throughout this process, I tried to view the transcripts as data – not just reading the text superficially, but asking questions as I was reading such as ‘*What does this mean?*’ and ‘*How does the participant make sense of their experience?*’ (Braun and Clarke, 2013; 205). As I worked my way through the transcripts, I made handwritten notes of areas I thought were of interest and relevant to my research questions. Initial observations included the disappointment and anger the nurses were expressing towards the nursing profession about receiving or witnessing poor care, yet they also expressed empathy for staff who were busy and working under pressure.

Some of the stories the participants told had been harrowing to listen to during the interviews. In listening to the recordings while reading the transcripts, strong emotions such as anger and sadness were evident, not just in the words that participants used, but in the tone and way the words were said. For this reason, I made notes of emotions

on the transcripts so that I would not lose this when I was working on analysis from the written text.

5.3 Phase 2: Coding all data items

Now familiar with the data and having some idea of the broad issues participants were talking about, the next step was to begin to code the data.

Ultimately, you want a comprehensive set of codes that that differentiates between different concepts, issues and ideas in the data, which has been applied consistently to the data. (Braun and Clarke, 2013:211)

Working through the text, I decided whether each section fitted a code I had already used (beginning with those codes used in the pilot interviews); was saying something different therefore needed a new code; or was not relevant to the research question and therefore not coded. For those items not coded, I wrote 'NC' in the margin so that when looking back at the data item I knew the section had not been overlooked.

The names of codes should capture what is said in the data to the extent that they can 'stand-alone' and still be understood.

Table 8 below shows an example of the initial codes applied to extracts of the James's (04) interview transcript. A small section of text has been omitted as although a pseudonym has been used, there was a minimal risk that the text could be identifiable.

Table 8

Extract	Code
<p>Unfortunately, after seven weeks, the pregnancy didn't continue and she was told she'd have to have a medical miscarriage [text omitted] so we were asked to come into hospital to go through that process. Leading up to that point everything, you know I thought the service was excellent and we were kind of handled with dignity and respect you know through a pretty difficult time. But it was the experience at the hospital which left me with a pretty horrible taste in my mouth; you know we'd been asked to turn up to a ward at a certain time and as you can understand we were both pretty gutted you know and in a pretty horrible state anyway and when we got to the ward we were just told sit in the corridor for, you know the nurse is on her break or something or whatever having a coffee. So we sat there for about forty five minutes and had to go and ask again you know, if someone's going to see us and we were eventually taken</p>	<p>NC (description of experience)</p> <p>Positive Experience</p> <p>Feelings about the poor experience</p> <p>Impact of the experience</p> <p>Staff visibility and accessibility</p>

<p>to a room and kind of left there for another hour without anyone coming in at which point you know, we didn't know what was going to be happening, what to expect and obviously we were both in a pretty bad emotional state. We were seen by a doctor who was going to explain the procedure but you know his first words to us were you're here for a termination which I said you know well that makes it sounds like this is something that we've, you know the pregnancy was something we didn't want which is you know very far from the truth but you know he didn't really respond to that and he went onto explain what would happen and we'd be given medication.</p>	<p>Being avoided Staff backing off Being Vulnerable</p> <p>Level of information</p> <p>How complaints and feedback are received</p> <p>How complaints and feedback are received</p>
<p>There were some nice nurses that took some time with us and talked to us and you know expressed some sympathy but on the whole I found the nurses to be quite cold and dismissive of us which wasn't really what I would want in that situation or my wife would want. So I mean we left it, we got discharged at like one in the morning and we were both pretty distraught after the experience; it was sweetened somewhat by the medic that did the last procedure, you know took loads of time with us you know kind of reassuring my wife that you know this was nothing, because she was quite concerned that she'd done something to bring on the miscarriage or you know somehow it was her fault but the medic took you know a really long time with her and was really nice and that's what I would have expected from a healthcare professional. So it wasn't for a while after, I think I stewed about it for a couple of weeks, I know my wife didn't want to complain although she was pretty upset by the treatment so I write an email to the complaints department, I can't remember what they were called now they've got a snappy title.</p>	<p>Positive Experience</p> <p>Staff attitude</p> <p>Emotional Impact</p> <p>Positive Experience</p> <p>Deciding to complain</p> <p>Making a complaint</p>
<p>JM: I'm not sure what they are called.</p>	
<p>I kind of repeated what I've just said to you, you know this is the experience we had and you know I was pretty unhappy with it. Being a nurse myself I guess one thing I can imagine that they have a very difficult job on that ward and maybe there's some kind of protective mechanism kicks in where you do distance yourself a bit from patients to try and protect yourself from what's really a distressing job you know. I know that from my own practise that there are times when I'm stressed and I'm not supported by my management I do kind of back off my patients probably a bit more than I should, just to really protect myself because I'm dealing with you know violence, aggression and distraught relatives on a daily basis kind of thing. So, I wrote that email and sent it and they emailed back saying sorry about your experience but then asked me if I wanted it to be a feedback or a</p>	<p>Feelings about the experience</p> <p>Comparison with own practice</p> <p>Making a compliant</p>

<p>complaint and at which point I kind of second guessed myself, I kind of panicked a bit and thought well I thought I'd already complained, so I put down feedback and now I'm not sure if that's right or not. But I guess I felt like when I was stated like that you know then I was like we'll have to get your wife's name and date of birth and more information, I felt like I was kind of dragging her into something knowing that she wouldn't wanted to have complained particularly, so I put it as feedback and that was kind of the last I've heard.</p>	<p>Knowing the complaints procedure</p> <p>How complaints are received</p> <p>Needing consent</p> <p>Impact of relationships</p>
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5.4 Phase 3: Generating initial themes

I then wrote each of the codes onto a 'sticky' note. Using sticky notes meant that I could easily group and re-group similar items until I was happy that the sticky notes were grouped together around what might develop into initial candidate themes. I then mapped out various iterations of how I had organised and re-organised the codes:

Figure 4: Initial map of codes showing potential linkages



After further sorting and refinement, I organised the codes under seven preliminary candidate themes:

1. Tension between patient/relative and nurse role
2. Using Nursing Knowledge
3. Feelings and Emotions

4. Balance of power
5. Perceptions about staff
6. The complaints/ feedback process
7. Making it easier to complain

The reason the term ‘candidate theme’ is used at this point rather than ‘theme’ is that themes come from a deeper analysis of coded data. As Braun and Clarke (2006, 2013, 2021) strongly advise, themes do not simply ‘emerge’ from the data as frequently described in research papers, they are actively sought by the researcher through interpretation and analysis. A theme has a ‘*central organising concept*’ (Braun and Clarke, 2013, 2022) and I discuss this later in the analysis. At this point, while some of the candidate themes may (and did) develop into themes, they are more accurately features of the data that appear to ‘hang together’ and are grouped to allow presentation of the data in such a way that it will aid deeper analysis.

Diagrams (1 – 9) illustrate a ‘point in time’ of the progression and further refinement of the post-it note codes around each potential candidate theme. In each diagram, the circle at the centre is the potential candidate theme with the surrounding squares representing each of its related codes.

Diagram (1) Tension between patient/relative and nurse role

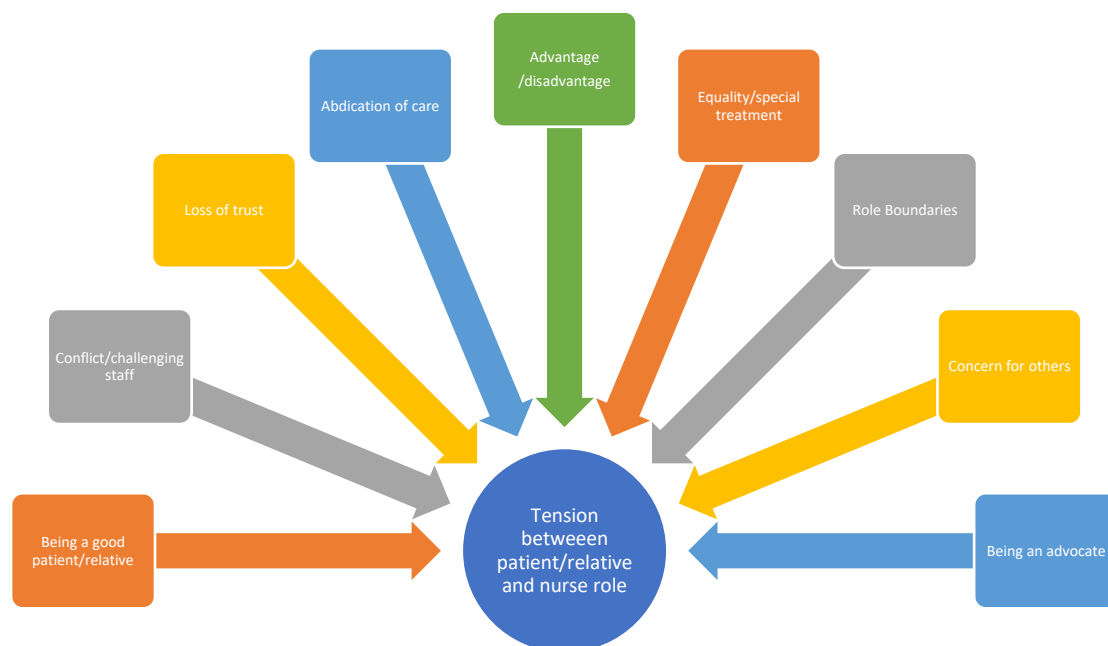


Diagram (2) using nursing knowledge

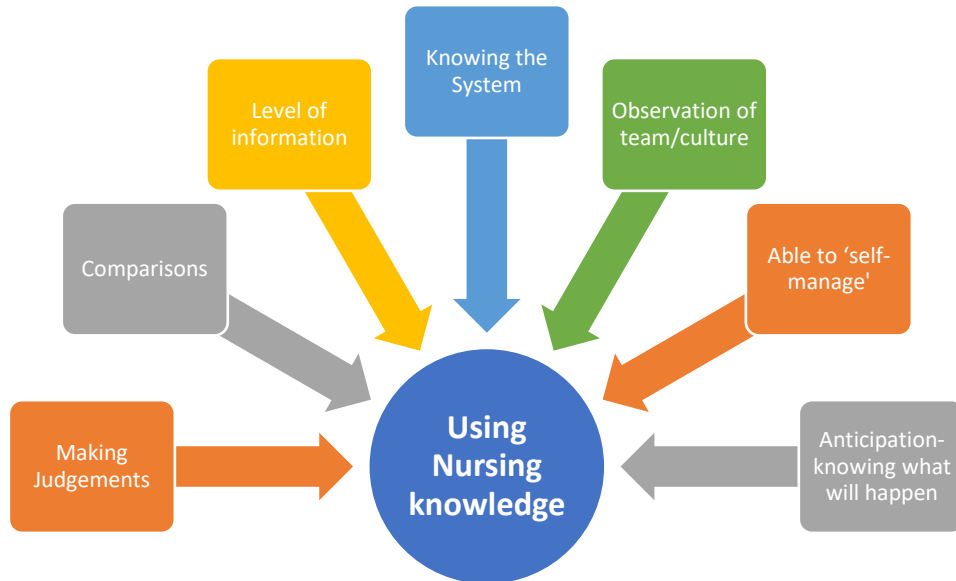


Diagram (3) Feelings and Emotions

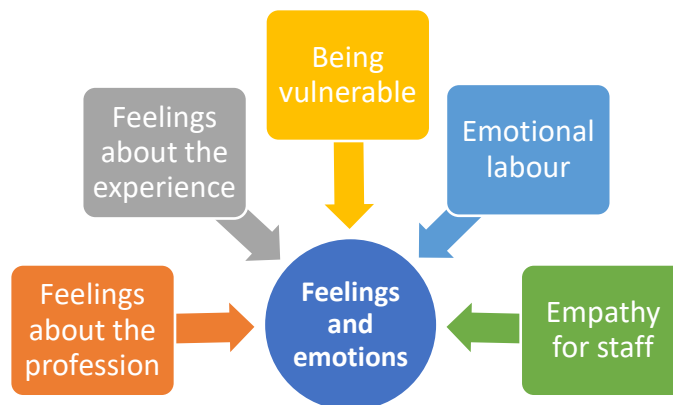


Diagram (4) Balance of power

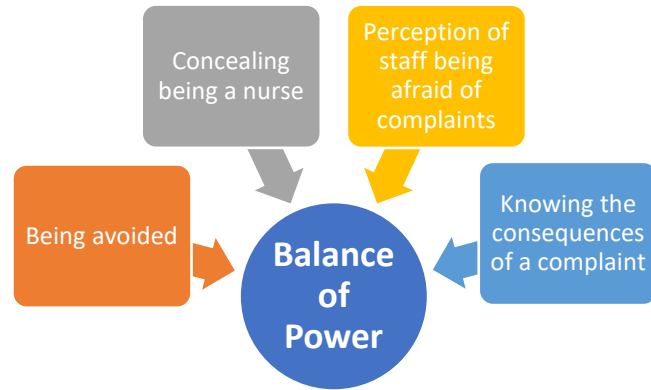


Diagram (5) Perceptions about staff

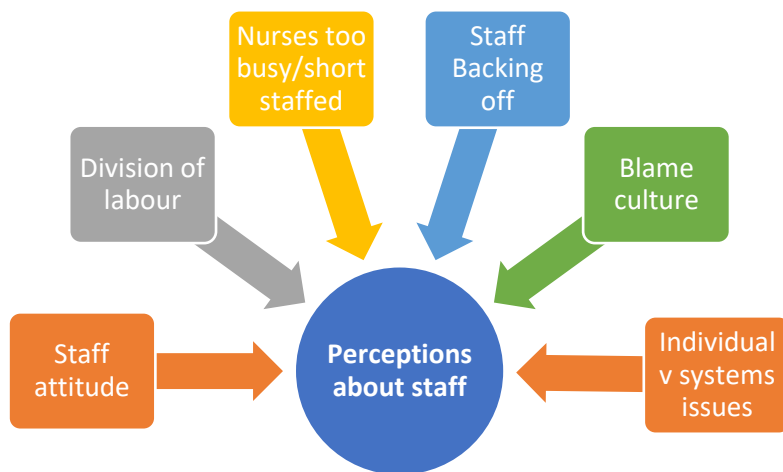


Diagram (6) The complaints/feedback process

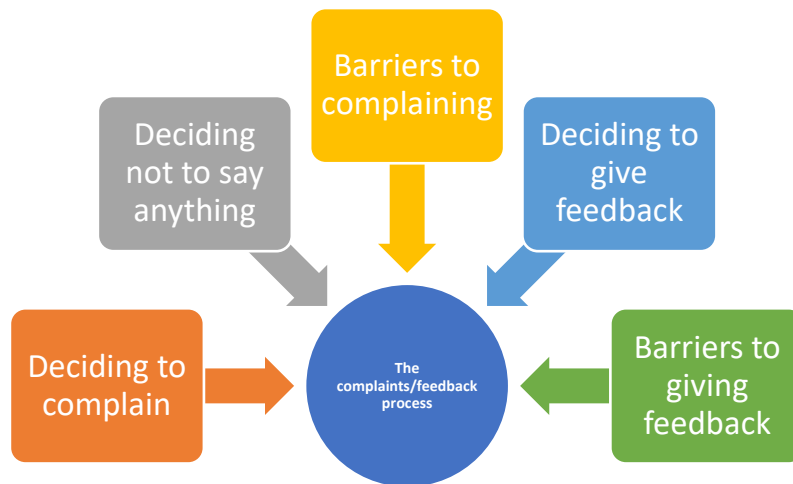
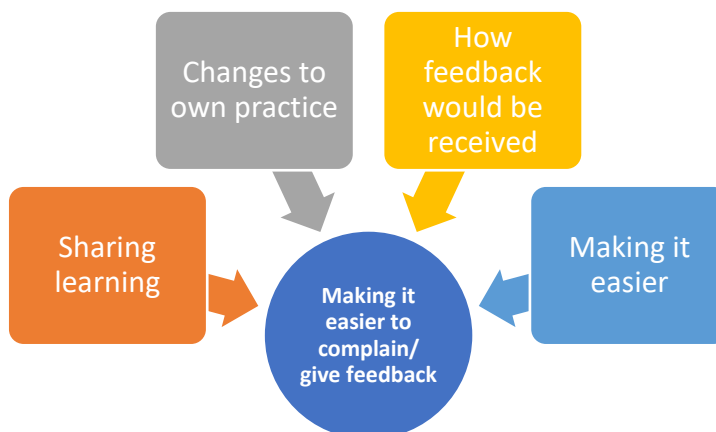


Diagram (7) Making it easier to complain/give feedback



Collating coded data

The next step in the analysis was to group together the data 'chunks' that had been labelled with the same code. Nowadays, researchers have a choice in how to manage and organise data, either by hand or supported by use of computer software. I decided to undertake my analysis using hard copy and by hand. Firstly, I prefer to work and edit on hard copy, and secondly, while computer programmes can assist with the management and sorting of data, particularly with large studies, the researcher must still undertake the analysis (Braun and Clarke, 2013). As this was a small study, a with

a relatively small data set, a manual system for coding and organising data was practicable.

As I was not using a software package, I needed to sort the data manually. There are several reported ways of doing this, for example, by cutting and pasting coded data items onto a word document or on to a table (Ritchie *et al.*, 2014). Initially, I typed each code as a heading on a word document then cut and pasted each section of coded data under its heading. This enabled me to look at the range of data from each participant under one code.

Identifying Patterns across the data

After coding, the next step in thematic analysis is to look for larger patterns across the dataset (Braun and Clarke, 2013). Organising the data onto individual word documents meant the number of pages to look through was unwieldy and it was difficult to read across the data set.

I decided to transfer the coded data on to a separate table under each candidate theme. Borrowing from Ritchie *et al.* (2014), I presented the data in columns under each code and by participant across each row. Within the tables, I made a note of the page number from the original transcript next to each entry so that it could easily be traced back as I anticipated continually moving back and forward between the coded data extracts and the raw data. Noting the page number also linked data extracts to the raw data in case I moved any item to a different code during the sorting process. I also noted the code numbers where a section of data could have been indexed under more than one code. It is important to stress that putting the data on to tables was not about developing a framework or code book, it was simply about having a visual tool to aid analysis.

Not all data items will contain every code. In reflexive thematic analysis the number of times a code appears is less important than the meaning and relevance to the research question (Braun and Clarke, 2013). I noted on the table where there were no codes applied to a data item. I also blocked the cell in grey so I would know that I had not missed something in transferring the data to the table. Being a visual learner, I colour coded each data item so that I could quickly recognise the participant – this also made it easier to locate the extract and refer back to the data item. This continued throughout the sorting process as I carefully re-read and placed each coded data item onto the table.

This is illustrated In **Table 9** below. The extract shows part of the data coded and grouped under the early candidate theme '*perceptions about staff*'

Table 9: Extract from Candidate theme 5: Perceptions about staff

Name	5.1 Individual v Systems issues	5.2 Blame Culture	5.3 Staff attitude	5.4 Staff backing off	5.5 Nurses too busy/short staffed	5.6 Division of Labour
01 None of these codes mentioned						
02 None of these codes mentioned						
03	<p>'So I was really quite shocked and like I used to think about campaigns like you know <i>'my name is'</i> I used to think for god's sake we're having a campaign to have nurses, where have we got to this is ridiculous till I sat there and I thought you know yes I can't believe where we've kind of got to in terms of, I just don't know and I think, I think part of it is systemic issues, there's no doubt. It's all the things you should know already, there's definitely staffing and skill mix issues and a real lack of visibility, I think there's big physical environmental issues that I would have been working on Nightingale ward so they weren't perfect but at least you could see people, you know and, but yes really quite kind of fundamental things that I was quite shocked to see'.(7)</p>		<p>A lot of nurses were not pleasant when you talked to them. (4)</p> <p>Things like no water, I mean I would just go the the shop and buy water because it was too much hassle – a snotty nursing assistant saying 'I'll be with you in 5 mins'(4)</p> <p>I Used to think – I can't believe we are having a campaign for compassionate care (7)</p>	<p>there were specific issues around him (dad) not getting mediation as prescribed and that we were kind of, we felt we were really kind of fobbed off in terms of getting to see a doctor.(5)</p>	<p>So, this probably went on for about two days, it might have been longer, the ward was extremely short staffed. There was one day, the day that actually culminated in the reason I'm concerned which happened the next day was there were no nurses visible on the ward at all, we were with him all day (1)</p> <p>I was mindful that he hadn't had any medication. By this time he was on Haloperidol but he also was on antibiotics and well we'd sat there, I don't know say from eight o'clock in the morning till six o'clock at night and he'd had no medication at all and I just chased nurses and literally chased nurses to say what's happening and was told the doctor is writing up a drug Kardex(1) Ward is unsafe (1) not enough staff (3)</p> <p>So I think, I don't know if the ward was in some kind of crisis with staff or they</p>	<p>Healthcare support workers come in to do basic tasks never asked how they were or if they wanted tea – I had to actively go and find [registered] nurses(4/5)</p>

					just didn't think but people, nobody came near us, nobody asked how we were, how my dad was and as I say I actively had to go and find nurses, trained nurses, to seek them out.(6)	
04	With the NHS complaints procedure you have to name and shame		<p>'Unfortunately, after seven weeks, the pregnancy didn't continue and she was told she'd have to have a medical miscarriage because it was a twin birth, so we were asked to come into hospital to go through that process. Leading up to that point [where she miscarried] everything, you know I thought the service was excellent and we were kind of handled with dignity and respect you know through a pretty difficult time' (1).</p> <p>Dr was supposed to explain but first words – so you are here for a termination – it was a miscarriage so not through choice (adding to distress) (1)</p> <p>'There were some nice nurses that took some time with us and talked to us and you know expressed some sympathy but on the whole I found the nurses to be quite cold</p>		<p>we'd been asked to turn up to a ward at a certain time and as you can understand we were both pretty gutted you know and in a pretty horrible state anyway and when we got to the ward we were just told sit in the corridor for, you know the nurse is on her break or something or whatever having a coffee. So we sat there for about forty five minutes and had to go and ask again you know, if someone's going to see us and we were eventually taken to a room and kind of left there for another hour without anyone coming in at which point you know, we didn't know what was going to be happening, what to expect and obviously we were both in a pretty bad emotional state (1).</p> <p>you know we were told that a certain nurse would be looking after us but then we only saw her a couple of times (5)</p>	

			<p>and dismissive of us which wasn't really what I would want in that situation or my wife would want'. (2)</p> <p>'It [the experience] was sweetened somewhat by the medic that did the last procedure, you know took loads of time with us you know kind of reassuring my wife that you know this was nothing, because she was quite concerned that she'd done something to bring on the miscarriage or you know somehow it was her fault but the medic took you know a really long time with her and was really nice and that's what I would have expected from a healthcare professional. (2)</p>			
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Reviewing the data extracts and codes

Placing the coded sections on the table meant that I could read across the different codes and consider whether they made sense. Sorting is a dynamic process and as I worked through the data on the table, I discovered that some codes seemed to fit together well under their candidate themes, but some seemed to overlap or say the same thing. For example, I could see similarities between data coded as '*deciding to give feedback*' and '*deciding to complain*'. When reviewing each of the extracts relating to these codes, often I could not decide which column (therefore code) the coded text fitted best under.

Candidate themes are provisional and develop as the analysis progresses – some will remain as themes; some develop into something more abstract; and others will be let go (Braun and Clarke 2013: 227).

For example, having reviewed the extracts and gone back to the data set, I felt the candidate theme '*Making it easier to complain*' fitted better as a code under *the complaint/feedback process* rather than as a candidate theme in its own right. In some ways this was surprising. As a candidate theme, making it easier to complain relates directly to the second research question. However, looking at the data and reconsidering, there was no real central organising concept that described how the codes worked together. '*Changes to own practice*' and '*sharing the learning*' didn't seem to fit.

At this point I went back to the post-its and re-organised the codes under candidate theme '*the complaint/feedback process*' and I created a new candidate theme '*service improvements*'. At this point the analysis was still largely descriptive as reflected in the candidate theme names.

The following **diagrams (8) and (9)** show the revised candidate themes in the circle, surrounded by the newly appointed codes.

Diagram (8)
The Complaints/Feedback process

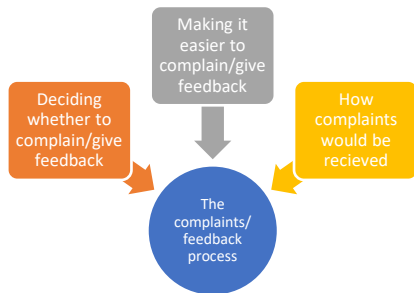


Diagram (9)
Service Improvements

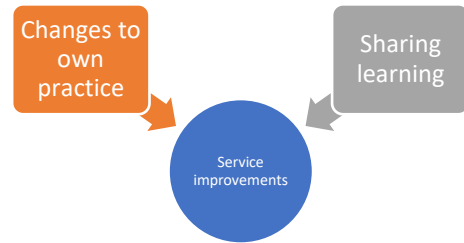
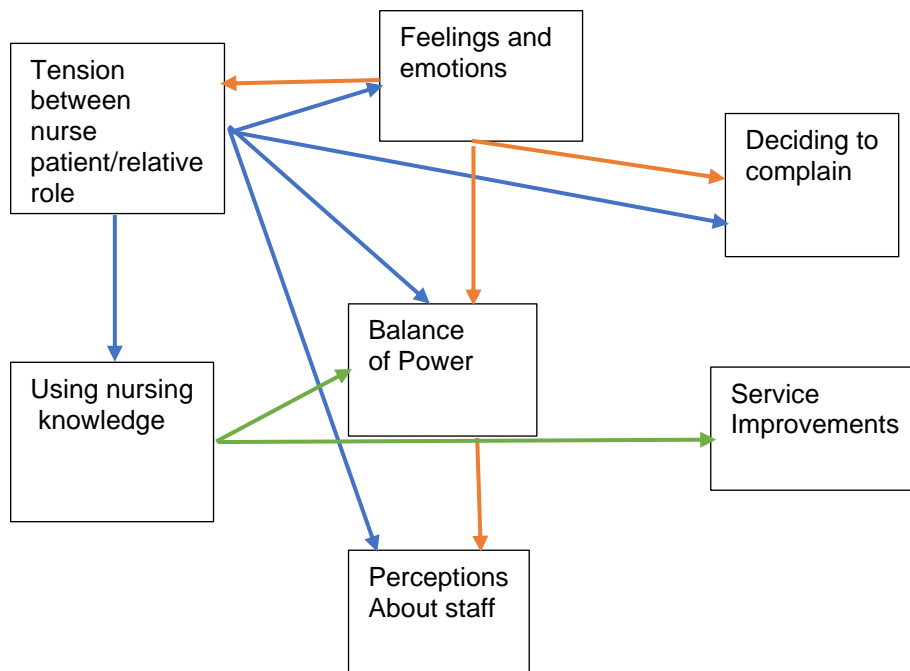


Figure 5 below shows a summary of the initial candidate themes with the arrows showing the and the linkages between them. As can be seen, '*tension between the nurse and patient/relative role*' links directly with most of the other themes suggesting that this may develop into an overarching theme. The same is true of '*feelings and emotions*'. However, further analysis would be required to understand whether this was in fact a theme, or whether codes within this theme fitted better with other themes.

Figure 5: Illustration of potential candidate themes and the linkages between them.
Candidate Themes Phase 3



5.5 Phase 4: Developing and reviewing themes

In reflexive thematic analysis the themes should tell a story while staying true to the data as the analysis moves beyond surface meaning to analysis which is critical and theoretically informed (Braun and Clarke, 2013). This development happens in three ways:

1. By revising the coded and collated data
2. By going back to the whole data set
3. By letting things go

Revising the coded and collated data

The next phase in my analysis involved looking at each section of coded data under each candidate theme and asking some further challenging questions. **Table 10** below shows an extract of my notes and thoughts from revising candidate theme '*Balance of Power*' and the data coded '*concealing you're a nurse*'.

Table 10: Extract from notes on the analysis of candidate theme 4: Balance of Power

Code 4.1 Concealing you're a nurse

Data extract/ summary by code	What are the characteristics from reviewing the coded text? Initial thoughts on 'what is being said here?' What is interesting about the data?	Theme/pattern development
01 Nothing coded		
02 Nothing coded		
03 You don't publicise you are a nurse – Not sure why – but you don't.	Unwritten nursing code? Part of the nursing culture?	
04 Nothing coded		
05 Nothing coded		
06 I try not to say I'm a nurse, but then I might ask something that gives the game away and I try not to do it. I try not to use professional terms or anything, but then I ask something and they'll say, "how does she know?". (9) [the older nurses] were nice, very matter of fact, didn't talk to me a lot but didn't really recoil a lot either. I would say it was the younger ones who probably felt more intimidated. Didn't ask about my nursing experience – just "oh, you're a nurse" and that's the recoil. (9)	Here she talks about concealing the fact that she is a nurse. Younger staff 'recoiling' because they feel intimidated. This is evident when they don't enquire about her experience as a nurse – but she is also making a judgement that she (and her relative) will be treated less favourably because they are nurses. Why do nurses feel the need to judge each other in such a negative way? Nurses work with other nurses every day and observe each other's practice so why is it different when they are patients or relatives?	How does this impact on their ability to give feedback? Being knowledgeable and having an insider view of systems – BUT hide this fact – want to fit in with other patients. How do you give feedback if you are concealing who you are and how does that influence the actual experience of care – increased stress/ anxiety from the dual role ?
07 'I don't like people to know what I do but once they know there is nothing I can do about it'	Anticipation of different, less favourable treatment? – powerless Or – once they know – power balance?	Going back to the transcripts for context – the duality is again apparent – is 07 saying I don't want them to know – but I let them know by the language I use? – the power is therefore in my favour? I have control

The next iteration of candidate themes

The following diagram (**Figure 6**) shows the next refinement and iteration of the candidate themes. Below the diagram, a brief summary of each potential candidate theme and subtheme illustrates the development the analysis.

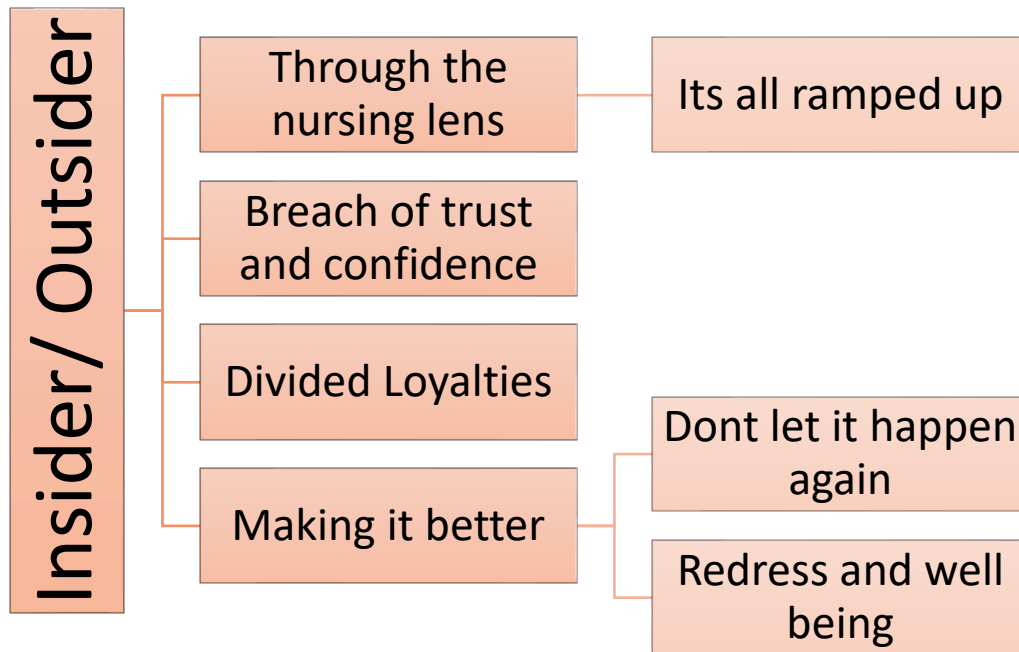


Figure 6

Summary of candidate themes

In developing this phase of the analysis, keeping a reflexive journal aided the process of moving back and forward between the whole data set and the clusters of codes/ initial candidate themes. As discussed, the phases of Reflexive Thematic Analysis are not linear. Much of the analysis from this point developed through phase 6: writing up, through familiarisation notes, reflexive journaling, and early drafts of the thesis. The following summaries are based on extracts from the reflexive journal. They illustrate a point in time in the analysis.

Insider/ outsider

The overarching theme insider/outside is key. It explains the dual role the participants occupy in being nurse patients or nurse relatives. It is overarching because it spans across all other themes.

Candidate theme 1: Through the Nursing Lens

Through the Nursing Lens developed from the initial candidate theme 'using nursing knowledge'. It describes how the nurse/patients and nurse/relatives view the world they find themselves in. Through the nursing lens, they assessed

- the clinical condition of themselves or their relative
- standards of care
- the wider culture and environment

Potential Subtheme – 'it's all ramped up'

At this point in the analysis, there appeared to be a lot of data sitting under 'through the nursing lens'. This led to the consideration that there may be subthemes sitting under this candidate theme.

Looking again (and again) at the data led me to reflect that it in addition to the way the nurse/patients and nurse relatives viewed the world, an important factor was the way their insights and knowledge influenced **how** they experienced the world. From the data, there was evidence that there were advantages to being a nurse including; knowing the system, knowing what to ask, and being able to challenge. Nevertheless, there were also disadvantages such as knowing too much, anticipating the worst and recognising when standards were not being met. There was also evidence that disadvantages were due to staff attitudes towards the nurse patients and nurse relatives, often because of their nursing role. These factors contributed to an increase in anxiety for participants.

At this point the idea of heightened anxiety became a candidate subtheme of through the nursing lens. The provisional title for this candidate subtheme came from one of the participants who described the heightened feelings and emotions of the experience as being '*ramped up*'.

Candidate theme 2: Breach of trust and confidence

Breach of trust and confidence arose through moving the data coded 'trust' to candidate theme 'feelings and emotions'. Feelings and emotions described a feature of the data but moving trust here got to the heart of what I felt the data was telling me. The participants expressed strong emotions about trust. Sometimes this was explicit, but more often what they said described or hinted at the concept of loss of trust. This led me to consider more deeply '*what is at the heart of the loss of trust? What does it mean?*'

The Code (NMC, 2018) presents the professional standards that nurses, midwives and nursing associates must uphold in order to be registered to practise in the UK. It is structured around four themes – prioritise people, practise effectively, preserve safety and promote **professionalism and trust**. Trust is therefore explicit within The Code (NMC, 2018).

I considered how trust is at the heart of any patient/ healthcare professional relationship and the restoration of trust is at the heart of good complaints management.

Given the duality of the participants' role I also had an idea that there may be a link with the loss of trust between patient and provider and the implied term of breach of trust and confidence within employment law. However, on further reading and reflection I felt this would move the focus from the participants primary role as patients and relatives and was beyond the scope of this study. As the analysis and development of this candidate theme progressed, I decided to let this idea go.

Candidate theme 4: Divided Loyalties

The candidate theme Divided Loyalties was about deciding whether to complain. Loyalties are divided on many levels;

- between nurse relatives and their loved ones,
- Nurse patients/ relatives feeling sorry for staff
- employer/colleagues.

The insider/ outsider overarching theme was key here. Divided loyalties were about role boundaries. The data from which this candidate theme was constructed linked strongly to the candidate theme 'through the nursing lens'. At this point in the analysis I began to question whether this candidate theme was foremost about the impact of blurred boundaries participants experience and whether re analysing the data would produce a more coherent theme and overall story.

Candidate theme 5: Making it better

Making it better related to two ideas; 1. Making the service better 2. Making the nurses better in terms of wellbeing and lasting impact. This was the weakest and most frustrating part of the analysis. I was not sure whether making it better was one theme, two separate themes, or two subthemes of a theme that was yet to be developed. While the data within this candidate theme held a powerful narrative, the link and relevance to the research question were not clear. At this point, I revisited the aims and objectives of the study to make sure I was analysing

data relevant to the research questions whilst ensuring that I was not trying to make the data fit the questions.

As can be seen from the summaries, the analysis at this point was beginning to develop, but as the summaries show, the central organising concepts were not yet fully developed. My other concern was that although the candidate themes were constructed from patterns across the data set, the focus was very much on the participants story and not necessarily directly answering the research questions.

I continued to go back and forth between the full data set, the coded data tables and the reflexive journal. However, it was not until I began to write up drafts of the analysis that I developed the level of deep understanding required to interpret some of the meanings that lay beneath the data.

5.6 Conclusion

This chapter charted the progress of data analysis from familiarisation and coding to the development of candidate themes. This was not a neat linear process, but a convoluted course that involved going back and forth between data items, tables and the whole data set. It involved sorting and re-ordering codes and working on the linkages between codes and potential candidate themes until the analysis began to develop into a story that was beginning to make sense.

The following chapter presents the final phase of my analysis.

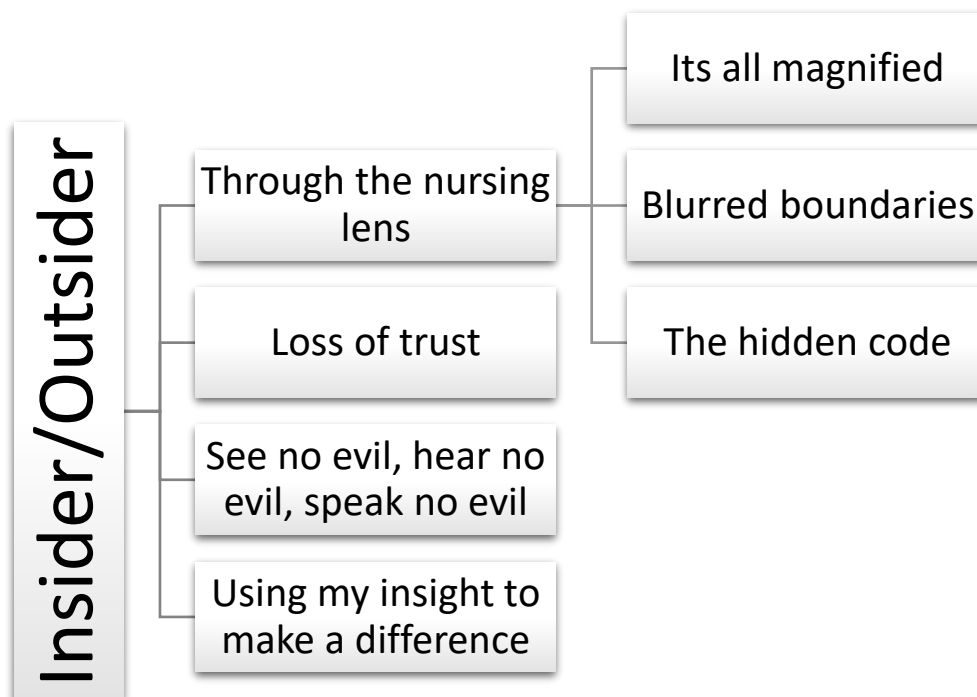
Chapter 6: Final phase of analysis

6.1 Introduction

In this chapter I present the findings from the final phases in my analysis. One of the strategies suggested by Braun and Clarke (2022) for assuring the quality of reflexive thematic analysis is that before settling on a thematic structure, it can be useful to formally present the analysis. I was fortunate to have the opportunity to present my findings to the Programme Director, senior teaching and research staff and fellows at one of the programme study days. Although, as Braun and Clarke (2022) point out, presenting can be stressful, the process was helpful in ensuring that the thematic structure was telling a coherent story. The feedback was encouraging in that the study day participants thought it was an interesting and important area of enquiry, and the questions asked at the end of the presentation facilitated a further review and development of the analysis.

The following diagram (**Figure 7**) illustrates the final thematic structure, below which a summary describes the central organising concept for each theme.

Figure 7: Final thematic structure



6.2 Summary of Themes

Overarching theme: Insider / outsider

Insider/outsider is an overarching theme that describes the duality of the nurse (insider) and patient/ relative (outsider) roles. It is through their insider/outsider position that participants provide a window into the experience of being a patient or relative that goes beyond that of a lay person. Insider/outsider is the thread that runs through the whole story, starting from how the participants experienced being in the role of patient or relative **through the nursing lens**; the **loss of trust** in the service, the wider health service, and the nursing profession when expectations were not met; the conflict over whether to speak up (**see no evil, hear no evil, speak no evil**); and finally, how participants reflected on their experience to suggest ways of making it easier to complain or give feedback and made changes to their own practice (**using my insight to make a difference**). **Table 11** below presents a description of each of the themes and subthemes.

Table 11: Description of themes and subthemes

<p>Theme 1: Through the nursing lens</p>	<p>Everything about the experience of being a patient or a relative was viewed <i>through the nursing lens</i>. The central organising concept for this theme is about how participants evaluate their experience against their expectations, through making clinical assessments, assessing standards of care, and their observation of the wider culture and environment.</p>
<p>Subtheme: It's all magnified</p>	<p>Viewing their world through nurses' eyes impacted not just on <i>what</i> they experienced but <i>how</i>. One participant described the increased anxiety caused by having nursing knowledge and insight and knowing when standards were not being met as being 'ramped up'. This seemed to capture the essence of how nurses experienced being a patient or relative and led to It's all magnified! becoming the heading for the first of three subthemes of <i>through the nursing lens</i>.</p>
<p>Subtheme: Blurred boundaries</p>	<p>Through the nursing lens develops further in the second subtheme blurred boundaries. In this subtheme, role ambiguity added to the complexity of how participants</p>

	decided on the standard of care they should expect as their position and perspective constantly moved along a continuum with their insider-nurse position at one end and their outsider-patient/ relative position at the other.
Sub theme: The Hidden code	The third sub theme of through the nursing lens, the hidden code , focuses on how care was experienced, often adversely, as a direct result of the participants nursing role.
Theme 2: Loss of trust	Building on the analysis of how care is experienced through the nursing lens, the second theme loss of trust explores the complex emotions that are felt, and tensions that arise when poor care is experienced or witnessed. Here again, the theme is underpinned by the participants' insider/outsider position. When care was poor the duality of their role led to feelings of loss of trust, anger and disappointment and of personal responsibility and shame— not only with the service received and staff involved directly in the care, but often with the wider nursing profession.
Theme 3: See no evil, hear no evil, speak no evil	This theme captures the construction of the participants' desire to complain but having to turn a blind eye because of the requirement for consent, the service not listening, or it just being too difficult, and the lasting regret some participants felt at not speaking up.
Theme 4: Using my insight to make a difference	The final theme explores how the participants used their experience as a patient or relative to suggest how it could be made easier for nurse patients and nurse relatives to complain, and how some participants tried to make a difference by sharing their experience with colleagues and making changes to their own practice.

6.3 Final themes

Theme 1: Through the nursing lens

This theme refers to the way participants viewed the world in which they found themselves as patients and relatives and how they used their nursing knowledge to try to make sense of their situation.

From the definition of a complaint by the SPSO presented in Chapter 1, dissatisfaction with a service occurs when the service fails to meet the standard of service expected. As discussed in the introduction, Van de Walle (2018) describes consumer satisfaction/ dissatisfaction with services as complex, taking into account expectations, experience and prior knowledge. When patients are dissatisfied with the level of care they receive, they often find it difficult to articulate what has gone wrong because they lack medical knowledge and technical understanding (Cohen *et al.*, 2021). During the interviews, it was apparent that when participants were describing their experience, they spoke as nurses.

The EDM Model suggests that when services exceed expectations (positive disconfirmation) then satisfaction occurs and when services fail to meet expectations (negative disconfirmation) dissatisfaction results. People that have high expectations of a service are more likely to be dissatisfied than people with low expectations (Van de Walle 2018). The language participants used was professional and expectations about standards of care were set against their clinical knowledge and experience as nurses. This was illustrated, for example, when Jennifer (P8) said, “the first time I went in I didn’t have a CT scan which is the gold standard for anyone who presents with diverticulitis”, and when Gemma (P1) described her perception of the lack of urgency in relation to her mum’s care “the doctor was just playing with medication ... he hadn’t even checked her renal function.” It was also evident in the extract below from Julie when she was in the Emergency Department as a patient.

“Nobody’s washing their hands, nobody’s putting things in the bin, everything’s just lying all over including dressings, nobody’s putting in Venflons right- all these things that matter. And, then the nurse came in and said, ‘I’m just going to give you this’ and put something in my vein. ‘What’s that?’, ‘Oh, its Morphine’, ‘Oh, right ok’. Didn’t check my name band....and I wasn’t monitored. So, I suppose it’s just my experience of, if you are giving something like that, you don’t know if there is asthma- you need to watch their breathing and all the rest of it, but nobody came near.”

(Julie: P7)

In the first part of this extract Julie's observations go beyond that of the environment being messy. Despite being extremely unwell, she observes what is going on around her in detail. She describes poor infection prevention and control practice and when she says '*all these things that matter*' it suggests that, in addition to her illness, she is worried about the consequences of the practice she is observing. Again, in the second part of this extract, through her nursing knowledge Julie (P7) was aware that the correct procedure for administering morphine was not followed. From her knowledge, she expected staff to understand potential side effects and to monitor her breathing, and the fact that this did not happen caused her increased stress.

In setting out their expectations, participants were often reflective during their interviews, drawing on and comparing their experience as a patient or relative to their past experience as a nurse in '*the good old days*' (Joan: P3). This was particularly so for those participants who were in more senior nursing roles or in roles that no longer involved direct patient care as the following extract from Joan (P3) demonstrates:

"I don't hanker back to the good old days because there were lots of terrible things happened in the good old days, but I couldn't quite believe where we had got to as a profession. Somebody like my dad would have been on at least 4 hourly obs. Work on a nightingale ward wasn't perfect but at least you could see people. I was shocked at the lack of fundamental care".

(Joan: P3)

Julie (P7) also compared her experience as a patient to days gone by:

"Nurses don't look like professionals anymore or that they care for themselves. How can they care for patients if they don't care for themselves? The social aspect of nursing has gone. There is no teamwork. The last ward was different – they did work as a team".

(Julie: P7)

Not only was Julie (P7) comparing her experience to that of the past, but she also illustrated that during her care episode the whole experience was not poor. In the last ward it was *different*, she observed good teamwork; a different culture resulting in better outcomes for patients. From the literature, there is evidence that one of the factors that influences whether patients will complain is that the whole episode of care was not poor (Mulcahy, 2003)

For participants working in clinical practice, their expectations as patients and relatives were based on comparisons with the area they were working in and on their current practice. For example, in the following extract, Samantha (P10) drew on her own experience as a surgical nurse to assess the impact of staff shortages on her mum's care.

“No one had been near her [mum]. She got back [from theatre] and they did her obs and then no one had been near her to give her a hand to do anything. She had a drain attached and she hadn't been up or anything, and the whole time I was with her I saw one nurse come in to see another patient and went back out. Whereas in my experience, you get patients back from theatre and you went to them straight away, do their obs, make sure they are ok, can you get them anything? She hadn't been offered anything”.

(Samantha: P10)

Participants' expectations were not just based on their direct clinical experience as nurses, but were also influenced by the wider environmental, cultural and political system of which they were part. In the following extract, Joan (P3) was discussing her views on the national campaign for compassionate care which, before she had been visiting her father, she hadn't thought was necessary.

“I used to think ‘for God's sake we're having a campaign to have compassionate nurses. Where have we got to? This is ridiculous’. Until I sat there and I thought, you know, yes, I can't believe where we have got to [...pause...] really quite fundamental things that I was quite shocked to see. A lot of nurses were not pleasant when you talked to them.’

(Joan: P3)

Some participants drew on tacit knowledge built from years of nursing experience. Their assessments were immediate and based on a 'feeling' that something was not right about the culture or the environment. For example, when visiting the care home to see his mother-in-law, John (P2) said “every time I went in – I suppose I'm very clinical being a nurse, sometimes – you go in and you are thinking mmmmm...[rolls eyes]”. Similarly, Joan (P3) commented “I think at the outset I felt the ward was unsafe”. Regardless of what their expectations were prior to visiting, from that point on their expectations were that care was not going to be what they would want it to be. Here there was the beginning of a feeling of mistrust, increased anxiety and a need for hypervigilance that becomes more evident later in the analysis.

Comments relating to the environment and culture featured in the stories told by most participants and frequently they included concerns about staff shortages. Participants often struggled with knowing the standard of care that they or their loved one should have received balanced with the standard of care it was possible for staff to deliver when short and under pressure. Staff shortages also impacted on the visibility and engagement of staff. This issue of recognising staff under pressure links across all themes, particularly *loss of trust* where empathy for staff is explored as an influencing factor as to whether participants will complain. The following extract from Jennifer (P8) illustrates this:

“So, I was admitted with acute pain and then I think, I was there for a long period of time, so the nurse literally puts you in the bed and then disappears, so nobody comes near you for a long time.....On the whole, people were just running round trying to do what they can”

(Jennifer: P8)

Jennifer (P8) recognised that staffing levels were impacting on the level of care she was receiving, but there was almost a resignation that long waits for care are to be expected - as an insider, staff were doing their best in difficult circumstances. Related to staffing levels, some participants spoke about the role of Healthcare Assistants and the amount of time they spent delivering direct care compared to registered nurses. Some commented that they were constantly having to look for registered nurses for information, to ask for care to be delivered, or to raise concerns.

“A lot of tasks were given to HCAs [Healthcare Assistants]. They don’t have the knowledge of the RNs [Registered Nurses] to nip things in the bud or to oversee care, but a lot of the care was just left to them”.

(Gillian: P6).

Here Gillian (P6) talks about HCAs not having the knowledge to ‘nip things in the bud’. This suggests that the lack of availability of registered nurses did not just impact on the standard of care delivered but had they been more visible, they would have been able to respond quickly to any concerns.

The conflict between knowing what level of care should be provided and understanding the context and reality of care delivery in a pressured environment was further evident in how participants tried to weigh up the balance as seen in Julie’s (P7) comment “I was having to

stand back and work out if I was being picky or realistic”, and in Gillian’s (P6) comment ‘It’s just that I like things to be done properly. Maybe I’m just being a bit paranoid”.

As discussed, the literature suggests that lay people often find it difficult to complain because they lack clinical knowledge. The participants in this study had knowledge. They knew the gold standard for practice, but they also had knowledge of the reality of working in busy wards and departments. As seen in Gillian’s (P6) comment ‘maybe I’m just a bit paranoid’, there were times when some participants second guessed what their expectations should be and whether in fact they had cause for complaint.

Subtheme (i) It’s all magnified!

A specific aspect of this theme was not just *what* the participants experienced, but *how* they experienced being a patient or relative. While having nursing knowledge could be an advantage, at times, for some, it could also be a disadvantage.

As evident in the literature (Salmond 2011; DeMarco *et al.*, 2004; and Zeitz 1999), having clinical knowledge increased anxiety as participants anticipated likely outcomes, often fearing the worst. For example, when Julie (P7) was in hospital she asked the doctors directly if they were looking for liver cancer because she understood the meaning of the tests she was undergoing. “I said ‘come on, I’m a big girl, I can take it’. Having knowledge meant there was no time to take in and process a diagnosis given by the doctor, or for reflection on what she had been told – she had already considered the worst-case scenario based on what she knew from the tests.

Gillian (P6) also anticipated the worst when she heard about the tests and investigations the doctor had ordered.

“When I knew what tests they were doing I knew what they were thinking about before they told me. When they said they were going to do an MRI, I knew exactly what they were looking for before they even said it and that’s a worry and then you think ‘*Oh, I’d rather know*’ but then you get yourself worried for nothing”.

(Gillian: P6)

In line with the evidence (Salmond, 2011), one of the strongest patterns across the data was participants inability to switch off, to stop seeing everything through the nursing lens. What was different for the participants in this study was the additional in fear and anxiety caused by

recognising poor standards or practice. This was articulated by Gillian (P6) in a way that seemed to capture the essence of this subtheme.

“Being a nurse is a help and a hindrance. I wish I could just step back and let it go. As a member of the public you have concerns, but this is just ramped up by having the professional knowledge to go ‘this is just absolutely wrong’ ”.

(Gillian: P6)

As a lay person, without clinical knowledge and knowledge of professional standards and procedures, much of what may go wrong may go unseen. However, for the participants, taking in the wider environment and being able to compare it to their knowledge of standards caused additional stress and anxiety both personally and professionally as can be seen in the following extract from Joan (P3).

“I think it makes you feel, it compounds it, it makes you feel kind of worse and as I say, I felt really professionally challenged because I was thinking, well, I’ve got a code of practice and I can see stuff, you know....so yes, I think it makes the whole situation worse, compounded by the other issues you know about.”

(Joan: P3)

For some nurse relatives, while anticipation and fearing the worst was about their loved one’s clinical condition, often anxiety was heightened when clinical knowledge was combined with knowledge and understanding of the wider system. The following extracts from Susan (P12) were selected to illustrate this because they tell the story well.

In the extracts below, Susan (P12) was visiting her son in the High Dependency Unit (HDU). The extracts give an example of how having nursing knowledge can impact on anxiety and how that anxiety can escalate as situations progress. Although she was there as a mother, it was as a nurse that she made assessments of her son’s condition and she used that knowledge to challenge the decision to move him to a general ward.

The next day there was a change of staff in the High Dependency Unit. The first thing they said was ‘*oh we’ll need to get him [son] out of here and up to the ward*’ and that’s the first time I sort of thought ‘get him out of here today?’, even that terminology was like, didn’t sit well with me and I said do you think he’s well enough?....through the day he had perked up, but me being the nurse, I was watching his temperature fluctuate and at times he was sweating and I thought ‘*Oh, something’s not right*’, but I thought

maybe it's just me being an over protective mum and having some knowledge. I think it's a dangerous thing in some ways, or maybe you just become a wee bit more anxious about things you think are causing a problem.

(Susan P12)

Comments such as '*get him out of here today?*' also hint at Susan's wider knowledge of the system and the need for patient flow through the hospital. The phrase used had made her question whether he was being moved because he was clinically well enough, or whether he was being moved because of systems pressures and a need to create capacity in HDU. Although as a nurse she recognised her son's signs and symptoms meant something might be wrong, in line with the findings of Salmond (2011), her role as a nurse was completely intertwined with that of being a mum. She was unsure if she was right or overanalysing the situation so she did not speak up at that point. On transfer to the ward Susan's (P12) anxiety increased further.

"...now 2 hours after he came and nobody's still done a set of obs on him and I was watching his drips and things go in and thinking, 'right nobody has even checked his ketamine infusion or his morphine infusion' so, you've got two syringe drivers and nobody is looking at these....I know they have to be looked at more than every 2 ½ to 3 hours"

(Susan: P12)

Having questioned whether her son was well enough to leave HDU, Susan's anxiety was compounded by having identified gaps in her son's care on transfer to the general ward. While step down from HDU to the less intense nursing in a general ward, with a lower nurse patient ratio, can be stressful for patients and families, Susan's anxiety was based on her 'insider' knowledge of standards and procedures not being followed. That evening, Susan (P12) received a call to say her son's condition had deteriorated.

"He was not breathing well and a really high temperature. I said, 'I knew it'. So, I was really angry... 'I told you he wasn't ready to come out. He was such a sick boy and I just thought 'nobody saw that' you know. They didn't appreciate how sick he was and how worried I was my son whose life depended on people doing a blood pressure, taking a temperature, you know, changing a bed sheet, checking that all these medications were being pumped into his frail body and they didn't do it. I had the insight as to something wasn't right and I couldn't get anybody to listen."

(Susan: P12)

Within this extract, there is an explicit feeling of anger, but underlying that, there is also a feeling of personal responsibility and powerlessness when Susan said, "*I had the insight as to something wasn't right and I couldn't get anybody to listen.*" Listening to the recording of this extract, what also came across was the frustration and loss of control felt by Susan (P12). In line with the findings identified in the literature review, loss of control, although not always stated explicitly, featured across many participants accounts of their experience. Again, what was different about the participants in this study was that loss of control was not just related to role boundaries, but was exacerbated when participants could see when care was not meeting the standard they expected but were unable to speak up of felt they were not being listened to. Role boundaries are explored further in the following sub theme.

Subtheme (ii) Blurred boundaries

The concept of blurred boundaries captures the construction of the nurse patient/ nurse relative role on the insider/outsider continuum with 'being a nurse' at one end and 'being a patient/relative' at the other. It is an interesting, yet sometimes subtle theme that relates both to the ways in which the participants constructed their own internal meaning and identity, and how they wanted to be seen by other healthcare professionals. Where the participants were on the continuum was fluid. It moved constantly depending on their situation and often linked to feelings of vulnerability and loss of, or taking, control. This reflects Salmond's (2011) study where she found the nurse-self roles and family member- self roles were completely intertwined. The impact of role boundaries on complaining featured in four different ways. Firstly, there was an element of professional pride – wanting to be perceived as knowledgeable and helpful; the second related to expectations of staff about the participants role; the third related to family members expectations; and the fourth related to the stereotype of the nurse as complaining patient.

For Shirley (P5), the blurring of her patient and nursing role caused distress during what should have been a routine GP consultation. She was very conflicted about going to see her GP about her chest infection. She felt pressured to go by her family, but she 'didn't want to be seen as someone who didn't understand that antibiotics wouldn't help' (Shirley: P5). She went on to say that when she arrived there were posters everywhere not to expect antibiotics which made her feel even more uncomfortable. As a patient, she felt tearful and vulnerable, but at the same time, as a nurse, she wanted to be seen to be knowledgeable. Following a difficult consultation, the GP did prescribe antibiotics. This had a direct impact on Shirley's decision not to complain about the GP's attitude and the way she spoke to her because she was now less confident about her own knowledge. Like the subtheme '*its all magnified*', in some cases

blurred boundaries also led to increased anxiety and stress caused by role ambiguity and conflict. Participants wanted to be treated as equal to other patients, but at the same time they wanted to be seen as different and treated differently – as knowledgeable healthcare professionals that know the system.

The literature review found some evidence of nurses patients and nurse family members being concerned about how they were perceived; either modifying their behaviour to form good relationships with staff so that they had access to clinical information (Salmond 2011), or as stereotypical complaining nurse patients (Connor and Duke 2008). Unlike Salmond (2011), none of the participants spoke of being seen to be helpful to build relationships with staff to gain access to information. Rather, 'being helpful' meant not being a burden on staff.

During her interview, Jennifer (P8) was describing a situation where she was concerned about staffing levels in the ward and about frail elderly patients being boarded patients to other wards. (Boarding is a practice where patients are moved to another ward to create capacity for admissions).

“The staff were just run off their feet really, and what used to happen was about 11 o'clock at night they would say 'there's no beds to bring the patients in tonight' so they would board out which is a phenomenon I thought had all stopped from the days when I was a [hospital] nurse. So, I was not boarded because I was a good patient in as much as I was self-caring and all I was needing was intravenous antibiotics, bloods done... and there wasn't too much nursing involvement, but sometimes the nurses were boarding out old ladies in their 80's with dementia”.

(Jennifer: P8)

In this extract, like other participants, Jennifer (P8) was not just concerned about herself, but about other patients in the ward and this explored further later in this theme, but what was interesting was the way Jennifer (P8) described the reason that she was not boarded '*because I was a good patient, self-caring*'. Being a good patient meant not adding to the burden of busy staff. Later in her interview, Jennifer (p8) went further: "I was trying to make beds, but they told me I couldn't because of infection control. I was desperate to do something because as nurses you don't just sit about'.

At the nursing end of the role continuum, Jennifer (P8) struggled to see her 'colleagues' busy and wanted to help. Like Shirley (05) in the extract above, it also suggests that Jennifer (08) found it difficult being in the patient role. In her nursing role she was confident, busy, 'doing

something' and in control. As a patient, she was told what to do - she 'the nurse' was not allowed to make beds.

The desire to be a good patient and help-out was also evident when Shirley (P5) talked about not expecting to get preferential treatment because she was a nurse,

"I don't expect to be treated differently to other patients but they [the nurses] are still kind of colleagues so if I can do anything to help - do what I'm asked to do then I will".

(Shirley: P5)

Many participants spoke of staff as colleagues. For them, 'colleagues' was a term used to refer to the wider nursing community to which they belonged. At this end of the spectrum, they were 'insiders' – part of the system that was delivering care that fell below their expectations. However, for Susan (p12), whose son was a patient in the hospital where she worked, 'colleagues' meant people she worked directly with. In the extract below, Susan's (P12) line manager approached her when she was sitting by her son in the High Dependency Unit.

I remember my line manager coming to see me that day actually, and she's looking at him and saying '*Oh, he doesn't look very well, but you know you can work from the office if you want, if you don't want to sit here*'. That was the first time I actually thought that within my own profession, and her actually being a nurse, I thought '*that's a strange thing to say, do you think I'd want to leave my child in this condition?*'

(Susan: P12)

In this situation, Susan's (P12) line manager was putting her in her nursing rather than her parent role. At that time, Susan (P12) did not want to be in her nursing role as a colleague, she wanted to be a mum. Unlike the evidence from the literature review that found nurse-family members whose relatives were being cared for in the hospitals where they worked were more likely to be included and part of the team or had a network of colleagues that supported them, much of Susan's (P12) poor experience was as a result of blurred boundaries with colleagues she worked with on a day to day basis.

The blurred boundaries between staff and nurse-relatives were evident in the accounts of other participants. This role ambiguity was often apparent in how much direct care participants wanted to deliver to their loved one compared to how much care they felt they were expected to deliver.

In Joan's (P3) case, staff would call her if her father was agitated and ask her and her mother to come in to help settle him. She was often left for long periods of time without support the support of ward staff.

"His management really involved a complete abdication of care to myself and my mother. I'm a mental health nurse but it's different when it's your father – to be sitting with someone who was completely not the person that you know, who is delusional, agitated, probably potentially aggressive, and needing contained."

(Joan: P3)

As a mental health nurse, Joan (P3) welcomed the involvement in her father's care and being included in decisions, but there were times that she felt staff neglected her father because it was just assumed she would deliver the care he needed. This also impacted on Joan's relationship with her father as she tried to fulfil the dual role of nurse and daughter.

For Gillian (P6), there was again a feeling of staff backing off and being left to get on with it.

"Nursing staff and health care assistants stepped back when I came in – they assumed I would give the care. One time I complained that she (partner) had not had a wash and I was just handed a basin – it was the same with sick bowls. Eventually I stopped asking and just helped myself. I shouldn't have to do that. I felt I was overstepping the mark."

(Gillian: P6)

Similarly, for Susan (P12),

"the support worker was passing and I asked if someone would change his sheets. I was told 'we're a bit busy but if you want a sheet you can do it yourself'. Luckily, I knew how to manoeuvre tubes and drains and things round. If I hadn't had that knowledge I could have caused him more damage.

(Susan: P12)

While participants were happy to help their relatives and as patients do as much as they could to be self-caring, the lack of visibility of staff and expectation that they would deliver care increased the burden and stress. However, for these participants there was also the feeling that because staff were 'rushed off their feet' (Joan: P3) the nurse relatives would take over

and fulfil their clinical role. While nurse relatives were sympathetic towards staff shortages, they also resented the fact that there was an assumption that they would just take over.

Role ambiguity between the nurse patient/relative and professional role was further complicated by the extent to which participants felt a duty of care and responsibility for other patients. For example, Jennifer (P8) observed the nurses leaving a lunch tray in front of a lady who was blind, rather than call a nurse she stepped into her nurse role and assisted the lady herself. Gemma (01) was not solely focussed on her mum's care. She also voiced concerns about other patients. "What got me was I had to advocate strongly for my mother, and I think for me, anyone else in that situation with no person to be a voice...." (Gemma P1).

For some participants there was a dilemma about their responsibility as a registrant to report unsafe practice they felt breached The Code (NMC 2018) to the Nursing and Midwifery Council. On more than one occasion during her interview Joan (P3), said that she felt responsible for what she was seeing, an example of which is evident in the extract below:

"The ward was unsafe. I was concerned not just for my dad but for the other patients and I felt responsible for what I was seeing... So, there was a real dilemma for me as a registrant too because the place wasn't safe for anybody, so there was the issue of my dad's care, but also as a registered nurse I was witnessing a really unsafe situation.....Also, there was the issue of the other patients in the ward not having anyone to advocate for them because the other three men didn't have any visitors so you're thinking at least my dad's got us to advocate for him".

(Joan: P3)

What was apparent during the interview was how visibly upset Joan (P3) remained as a result of her experience. What was also apparent was her anxiety and distress at the conflict she felt between her personal role as a daughter and her professional responsibilities as a nurse to act in an unsafe situation. *Blurred boundaries* contributed to the subtheme *it's all magnified!*

Another example of role ambiguity was when family members looked to the nurse relative to be in their nursing role. For some like Gillian (P6), they were happy to take on this role. Doctors were sharing information such as blood results with her and it meant she could keep track of what was happening. She was happy to take responsibility for explaining things to family members – "I knew what I was talking about, what was going to happen next and how to prepare them".

However, for others it was more stressful as the following extract from Samantha (P10) illustrates:

“There are 3 kids in my family. I’m the middle one but mum always sort of looks as me as the strongest because I’m a nurse and I have that extra bit of knowledge. It can be a good thing but sometimes it’s not. Like when my dad was ill, my brother and my sister would ask me stuff so I could explain to them. But, I knew all the side effects, and this could happen, and that could happen....so it was kind of, it was really hard. It was really hard knowing that things could go wrong from his operation. One of the things that happened to him was a bit life and death and I don’t think my brother and sister grasped that I knew. So, if they asked me, I would be like ‘oh no, he will be fine’. I just didn’t want them to know. I think being a nurse I’m very protective over them, like my brother is 2 ½ years older than me but I’m still very protective over them.”

(Samantha: P10)

Samantha’s (P10) nursing knowledge gave her insight into her father’s condition. She was anticipating the worst but having to filter information for her siblings. In addition to worrying about her father, she was supporting her siblings while holding her own anxiety and fear.

Pat (09) spoke of the time when her brother had been diagnosed with bowel cancer. She was put in conflicting positions when her sister-in-law asked her to act in her nurse role and her brother put her firmly back into her relative role.

“My sister-in-law used to say to me *‘please talk to [brother] as a nurse, because he won’t talk about cancer to anyone. I’d like you to talk to him’*. He wasn’t interested in having discussions about cancer. He was done and he saw no reason to chat about it. I tried a couple of times to get him to talk because that’s what everybody wanted, that’s what people perceived to be healthy. *‘Pat, he needs to talk about it’* and I had a sense of failure as a nurse and as a mental health nurse, because you know, I’m supposed to be able to get people to talk and I couldn’t even do it for my brother”.

(Pat: P9)

Pat (P9) went on to describe when she accompanied her brother to an appointment at her sister-in-laws request:

“My brother would say to me, *‘Don’t you dare say a word to the doctor you can come and listen but you can’t speak’* and that’s a very difficult position to be in and I could see all sorts of flaws in his treatment and could do nothing about it”

(Pat: P9)

The extracts from Samantha (P10) and Pat (P9) illustrate the additional pressure nurse relatives felt when their family members expected them to act in their nursing role. Linked strongly to the subtheme *it’s all magnified*, they were not only experiencing care they perceive to be poor but in as illustrated in Pat’s (P9) case, were unable to advocate for their family member and had to remain silent.

However, other participants did feel able to speak up and advocate for their family member. Gemma (P1), described how being a nurse and having professional knowledge gave her the confidence to challenge the doctor about her mum’s care. The GP was reluctant to admit her mum to hospital, so she actively used her knowledge of the system and her relationship with senior staff to influence her mum’s GP as can be seen in the following extracts.

“having sat down with him [the GP] and said we had serious concerns. I said I want her in hospital now and he said *‘ok we will try and get a bed but we might not be able to get a bed in [acute] hospital’*. At the time I was working in the health board and I said, *‘I will phone the Chief Executive now and will ask him for a bed’* and instantly that was a different reaction. I think she wouldn’t have got a bed if I hadn’t been working in the health board, if I had not had the level of understanding. I noticed the oedema on her abdomen and was able to flag that up. If I didn’t know how to spot that oedema and even the cyanosis around the lips and I wouldn’t necessarily have understood the significance. So, I think me being a nurse did have an impact on the doctor’s reaction and getting her into hospital. One of the hospital consultants told me if my mother had not been admitted she would not have survived.”

(Gemma: P1)

In contrast with some participants who felt a loss of power and control, being a nurse and having the confidence to challenge had shifted the balance of power for Gemma (P1). It enabled her to take control and influence the outcome for her mother.

Unlike Gemma (P1), and consistent with findings from the literature (Duke and Connor 2008), some participants were worried that being seen to be a troublemaker would impact negatively on the care they or their relative received. For some, the stereotype was re-enforced by

previous experience in their professional role as articulated by Joan (P3) in the following extract:

“I’m sure I had a big reputation as a troublemaker. Unfortunately, if you do prove yourself to be difficult as perceived by nurses, you’re likely to be responded to in certain ways unfortunately, and that can have consequences for the patient. You know as well if relatives are seen to be being difficult”

(Joan: P3)

Others were also aware of the stereotype and took steps to alter their behaviour to present a positive image. For example, April (P11) stated that she ‘didn’t want to be seen as another moaning relative’, and Susan (P12) not wanting to be seen as ‘the difficult relative’. They wanted to be seen in their professional role as helpful and accommodating and avoid any adverse consequences for their family member.

Julie (P7) was also concerned about how she appeared to staff: “I have knowledge, but I didn’t want to come over as being a smart Alec”. In her nursing role she was expected to have knowledge, but in her role as a relative she needed to conceal that knowledge. Later in the interview Julie (P7) went on to say, ‘nurses as carers are not the easiest – they can be really prickly’. Here, her own experience of dealing with ‘prickly’ nurse relatives influenced the way she wants to be seen as a relative, having knowledge, but not too much- *being good*. The idea that participants felt they had to conceal their knowledge and conceal being a nurse is explored further in the next sub theme *The Hidden Code*.

Subtheme (iii) The Hidden Code

The professional standards of practice and behaviour for nurses are set out in The Code (NMC 2018).

“Nurses, midwives and nursing associates must act in line with the Code, whether they are providing direct care to individuals, groups or communities or bringing their professional knowledge to bear on nursing and midwifery practice in other roles, such as leadership, education, or research. The values and principles set out in the Code can be applied in a range of different practice settings, but they are not negotiable or discretionary.”

(NMC, 2018)

The Code contains statements under the headings

- Prioritise people
- Practice effectively
- Preserve safety
- Promote professionalism and trust

Together, these statements signify what good practice by nurses looks like.

“It puts the interests of patients and service users first, is safe and effective, and promotes trust through professionalism”.

(NMC, 2018)

The Hidden Code is the third specific aspect of the theme *through the nursing lens*. It refers to the relationships between the participants and other health professionals, particularly other nurses. *The Hidden Code* is the construction of a world of avoidance, concealment and fear that links strongly to the participants’ experience being ‘all magnified.’

Many participants spoke of the general lack of compassion from healthcare professionals, for example, when James attended the hospital with his wife who had to have a medical miscarriage of their twins, staff did not know he was a nurse: ‘On the whole, I found the nurses to be cold and dismissive of us’ (James). However, *The Hidden Code* refers to the way participants felt they were treated as a **direct** result of their nursing role. In some cases, participants felt as if they were actively avoided because they were nurses, and in others, they actively tried to conceal the fact that they were nurses. The reason for this avoidance / concealment on the grounds of role was not always explicit. “You don’t publicise you are a nurse. I’m not sure why, but you don’t” (Joan: P3). “It was difficult. Luckily, I didn’t know anyone on that ward, although I had worked in the hospital doing a study, but it was difficult. My mother-in-law made sure they knew I was a nurse so that made it difficult” (April: P11).

“I try not to say I’m a nurse, but then I might ask something that gives the game away and I try not to do it. I try not to use professional terms or anything. I asked some questions that were pertinent about her bloods and they said ‘Oh are you a nurse?’ and I said ‘yes I am’. ‘Oh right, ok’ you could practically see them recoil, especially nurses that were considerably younger than me”.

(Gillian: P6)

Using the term *recoil* (Oxford Dictionary Definition: *suddenly spring back in fear, horror or disgust*) evokes the image of a strong reaction from the nurses to finding out that Gillian (P6)

is a nurse. This was particularly so for younger and possibly less experienced staff implying that having an expert patient or relative is a threat to staff.

Like the senior nurses in Duke and Connor's (2008) study, some participants felt they were actively avoided because of their nursing role. Julie (P7) was in different wards throughout her stay in hospital. On one ward she was told by a student nurse who was taking her blood pressure that the Registered Nurse didn't like her being in the room too long because she was a nurse. "*She doesn't like us being in here because of what you are*". "When I went into the last ward they knew, they knew. It must have been written down or handed over. Now I actually think that's why they avoided me".

(Julie: P7)

In being avoided, participants were not just outsiders in their role as patients and relatives, they were put into the outsider position by other nurses.

The following extract from Pat (P9) during her experience of being a patient, illustrates how, at first, she wanted to conceal her nursing role and wanted to be treated the same as other patients.

"I didn't tell people at first. I didn't want people to look at me differently, but actually that's not quite correct. In the first ward there were student nurses with their university badge on. I said to them, 'Look, I'm sorry if you recognise me' and this guy said 'yes' and I said, 'look, I'm just a patient like any other – just forget the fact that I'm a teacher. 'I'm just a patient like any other' and then one of the staff nurses came up and said 'Oh, I hear you teach student nurses at the university' and I said 'yes I do, but that's not really any concern for me right now. I want to forget it and that was for the nurses. I didn't want them to be on their guard. I didn't want them to be suspicious of me, or [...pause...] I just wanted to be a patient".

(Pat: P9)

Like *recoil*, Pat's (P9) comments about nurses *on their guard* and being *suspicious* also evokes an image of fear- one that she anticipates from the nursing staff looking after her if they look on her as a nurse, particularly as a nurse teacher, rather than 'just a patient'.

In the following extract from Julie (P7), she hears the nurses talking about her getting to go home for the evening.

“You don’t want – nobody should get special treatment either. We should all be treated the same, but there was a bit like...you know one of them [staff nurses] actually said outside the door ‘*well we wouldn’t do it for anyone else*’ and I thought ‘they said that about me’. So, I said to the girl when she came in ‘*what would you not do for someone else?*’.....she went ‘*I didn’t mean that the way it sounded*’ and I went ‘*but that’s exactly what you said*’. I don’t like to tell people what I do but when they know there is nothing I can do about it”.

(Julie: P7)

Nurses observe each other’s practice all the time at work, so it is interesting that this dynamic changes when the nurse is a patient or relative. *The Hidden Code* implies that if you are a nurse in the role of a patient or relative you are treated differently; The Code that upholds the standards of the profession and that states that people must be treated with ‘*kindness, respect and compassion*’ (NMC 2018) appeared not to apply when the patients or relatives were also members of the profession. Rather, in line with the findings from Duke and Connor (2008) they were something to be feared, avoided and not engaged with.

What is also interesting is that, while participants like Joan (P3) said they did not know why they tried to hide the fact that they were nurses, the fact that they did implies that they were, at some level, as ‘insiders’ they aware of and complicit with the *hidden code*.

The notion of staff recoiling, being on guard, suspicious and practicing avoidance presents an image of staff putting the patient (or relative) in the role of an expert observer that will catch them doing something wrong that may result in consequences for that staff member. However, the impact of nurses acting as if they are fearful and avoiding patients and relatives is significant, not only by adding to an already stressful situation for the participants, but the lack of visibility and approachability was impacting on good communication and the ability to listen to and sort any concerns as they happened.

Some participants did comment on the reason that nurses might be treated differently. Drawing on his own experience, John (P2) said, “I think it’s when you realise you know somebody is a nurse you automatically go, oh right, make sure this is done or that’s done and make sure it’s done the way it should be”. He went on to say “It’s hard not to take it [constructive criticism] personally. You automatically become defensive, but at the end of the day you are here for the patients.” (John: P2)

James (P4) spoke about a culture of fear in the area where he worked “It’s like inspection, but that’s not what it’s there for [*to cause fear*]. It’s there to improve things. You know, if we knew that an inspection can improve our practice we’d probably welcome it with open arms, but there’s certainly a culture where I work where folk will go ‘oh no, there’s an inspection’...I think it’s quite similar about complaints, I think we kind of fear it. James (P4)

However, there were occasions when participants deliberately used the fact that they were nurses to their advantage. Having been told she could go home from hospital, then told she had to stay for further assessment, Pat (P9) was very upset and angry. She disclosed her nursing role to get staff to listen to her.

“I felt through the four days that there were certain hoops I had to get through but nobody told me what they were, nobody told me what the game was and by the end of it I said, ‘I’m a nurse and I’m not happy with any of this’ and they said ‘Ok, we’ll get you to meet up with the Senior Charge Nurse’ ”.

(Pat: P9)

She no longer wanted to be treated the same as other patients. She was prepared to use her status as a nurse to express her dissatisfaction. She moved from a protective role – not causing the nurses to ‘be on guard’, to using her position as a nurse to do what she suspected the nurses were fearful of – patients using their nursing knowledge and power to catch staff out and get them into trouble.

The findings within ***The hidden code*** are illustrative of a culture of fear and blame where nurse patients and nurse relatives are afraid to disclose their profession for fear of being treated less favourably or avoided and where staff fear being watched and judged by knowledgeable patients and relatives. This links very closely with the next theme: ***Loss of trust***.

Theme 2: Loss of trust

The theme *Through the nursing lens* and the three sub-themes within were constructed from what participants experienced how they viewed the world in which they found themselves as patients or relatives receiving or witnessing care that did not meet their expectations. The theme *loss of trust* is the next phase in the story.

This theme developed initially from the analysis of the code *loss of trust*, a semantic code that was expressed explicitly by some participants like Susan (P12): “I left [my son] because even though they hadn’t done things, I trusted that they would do the right thing and they didn’t. They didn’t” (Susan: P12). However, although not all participants explicitly used the word trust, the loss of trust was implicit within the narrative. A systematic review by (N. Brennan et al., 2013) although under researched, mutual trust is fundamental to the patient-provider relationship. Through deeper analysis it became apparent that the issue of loss of trust was evident in stories of all participants and as the restoration of trust is one of the principles of good complaint handling, loss of trust became a theme.

This theme has many layers. Loss of trust affected different relationships and, in some cases, was having a lasting impact on some participants’ wellbeing. Linked to *its all magnified*, the loss of trust was felt more acutely by some participants because of their nursing role. From an insider perspective, there was an expectation that their colleagues (both those they worked directly with and colleagues in the wider sense) would uphold the highest standards and when their expectations were not met, there was anger and disappointment amongst most participants. They described not just losing trust in the service they received, but with the wider health service and the profession, an example of which can be seen in the following extract from Pat (P9):

“I felt immensely disappointed in my profession, in mental health nursing, mental health nurses and the care system we’re offering. I mean it breaks my heart; it really does”.

(Pat: P9)

For some like Susan (P12), the trust was broken with colleagues that she worked with every day; people that she had a professional and personal relationship with.

“All night I kept blaming myself for leaving him. I thought ‘I’ve left him there with those people and they’ve not done what they should have done, and that was I suppose

anger and sadness actually and the fact that these are people I work with every day and other people put their trust in them and I had lost that in just a few hours”

(Susan: P12)

The extract above suggests that while it can take a long time to build trust, when things go wrong trust can be lost in a very short period of time. The implication being that it will take a long time, if ever, to rebuild trust. This is illustrated in the next extract from Susan (P12) below, where the experience with her son has had a lasting impact:

“I will never, which is a sad thing, I will never view ward x as a safe place for any patient to be ever, ever. No one will ever take that away; you know that feeling will never leave me. Even to this day, when I say it, I think God, these poor patients. Now things might have changed, but I don't know....”

(Susan: P12)

Not only has her experience had a lasting impacted on her personally but it has influenced how she now feels about her place of work. Back as an ‘insider’ Susan (P12) does not fully trust that the care in ward x has improved.

The loss of trust was painful for Gemma (P1). The GP looking after her mother had been the family doctor for many years – ‘I mean he got a bottle of malt at Christmas’ (Gemma: P1). When Gemma (P1) felt that the care her mother received had been ‘substandard’ and that had she not threatened the GP with the speaking to the Board Chief Executive to get her admitted her mother might not have survived she was angry and upset.

I said *‘I trusted you implicitly, why didn't you?’* And I think he could see the disappointment, the lack of trust thereafter. I moved GP practice and mum did as well. I just couldn't trust him again.

(Gemma: P1)

Although Gemma (P1) did not work with the GP, they had a longstanding relationship. Gemma considered complaining and spoke to her colleagues at the NHS Board about the complaints process. In the end she decided not to complain “It was loyalty, I think, and you know, just time, we had been with him [the GP] for so long”. From the literature (Simmons, Powell and Greener, 2009) there are different options open to people who are dissatisfied with a service including exit, voice, exit and voice, and saying/doing nothing. In Hirschman's (1970) exit voice loyalty framework discussed in Chapter 1, the choice people make is often influenced by

loyalty. Gemma chose to exit and not voice, suggesting, according to Hirschman a low level of loyalty, however, it was her loyalty that prevented her from making a formal complaint about the GP. Not wanting to get people into trouble is a common reason for people choosing not to complain and this is explored further in the next theme, *See no evil, hear no evil, speak no evil*.

Although not everyone explicitly used the word trust, the loss of trust was evident in the stories told by all participants, particularly when they were witnessing procedures not being followed and when communication was poor. The extract below from Joan (P3) is an example of where loss of trust sits beneath what was being said:

The other thing that I was witnessing, or not witnessing, was observing – because you have a good look through the paperwork, well I did, and his care rounding records were indicating that he was receiving care rounding when we were sitting there and there was nobody coming to him.

(Joan: P3)

The nurses had recorded on the paperwork that they had delivered care to Joan's (P3) father at times when she was by his side and she therefore knew that care had not been delivered. She knew that the nurses had falsified records and were in breach of The Code. For Joan (P3) and others, the impact of loss of trust went further than anger and disappointment. Being let down by nurses left some participants feeling ashamed of the profession.

Linked to the feelings of personal responsibility for the standards of care participants experienced in *It's all magnified*, were the feelings of shame described by some participants "I felt completely ashamed of the profession" (Joan: P3). The intensity of feeling links strongly to *It's all magnified*. While anger and disappointment are focussed on the external world, feelings of shame are personal as illustrated in the extract below. For Pat (P9), her feelings of shame about the nursing profession also impacted on her relationship with her husband.

I took more of a back seat in the care of my mother-in law because my husband is the next of kin- except for the fact that my disappointment in my profession is mine, not his, and that I [...pause...] and that kind of sits between us. I, feel personally ashamed of everything I've done over the last 30 years because of what he's seen in the last 2 ½ years. So, it touches you in a really kind of personal way.

(Pat: P9)

To some extent the feelings of shame felt by participants may be underpinned by the Code (NMC 2018).

“You uphold the reputation of your profession at all times. You should display a personal commitment to the standards of practice and behaviour set out in the Code. You should be a model of integrity and leadership for others to aspire to. This should lead to trust and confidence in the professions from patients, people receiving care, other health and care professionals and the public”.

(NMC, 2018)

The extract above illustrates that the core values that underpin the Code go beyond the working day. It demands that the reputation of the profession is upheld ‘**at all times**’ and that there is a ‘**personal**’ commitment to the standards of practice. As was seen in the extract from Joan in *Blurred Boundaries*, for many of the participants, this included when you are a patient or relative. In the extract below, Susan explicitly talks about the code:

“I think there is an expectation that these are people that have the same morals and values and standards as you do, and as an individual I have high standards and expect high standards of people....and I expected them to look after him because that’s what we signed up to do. That’s our code of practice. It’s to do the best for people and they didn’t, and I feel completely let down by it. Let down by my own profession”.

(Susan: P12)

For a few like Pat (P9), the experience was still having a significant impact on their wellbeing:

I was just furious, I mean furious and I know I’ve got a real kind of, you can probably hear it now, a real emotional – ahhh! Just like a badness, like a, like a puss that’s sitting there, that is still full of anger you know.

(Pat: P9)

Mutual trust is at the heart of the patient-clinician/provider relationship (Chandra *et al.*, 2018) and when that trust is broken, there can be implications for future engagement with services. What was apparent with many of the participants was that the loss of trust was deeper than that of a patient-clinician provider. From the extracts above, the impact of loss of trust and the feelings of anger, disappointment and shame at being let down by the profession were deep and enduring. The overarching insider/outsider theme underpins loss of trust. As outsiders, in their patient/ relative role, they have lost trust with a service, as insiders, in their nurse role,

they are an integral part of the service, and often the profession, that has let them down. The insider/outsider theme continued as participants were faced with the decision about whether to complain about their experience.

Theme 3: See no evil, hear no evil, speak no evil

One of the interesting findings that felt apparent during the interviews, and was confirmed through the analysis, was that while participants were very keen to talk about their experience, even although this was at times harrowing and they often became visibly upset, they appeared less confident and more reluctant when it came to discussing whether or not they should have complained.

See no evil, hear no evil, speak no evil is an ancient proverb that means to turn a blind eye to wrongdoing. There are three elements to this theme. The first, *see no evil*, captures the construction of the participants desire to complain, but having to turn a blind eye because their relative expressly refused to give consent or because they were unable to ask for consent for fear of causing further distress. The second, *hear no evil*, captures the construction of the participants' desire to complain versus how open staff were to listen to and hear their concerns or complaints. The third element, *speak no evil*, captures the idea that there are those who, despite a poor experience, suffer in silence and say nothing. With hindsight, many participants wished they had complained, and this was a source of regret for some.

See no evil

When a third party such as a relative, friend, Councillor, MP/MSP complains on behalf of a patient, the patient's consent is required to enable a response to be sent. One of the issues the nurse relatives struggled with was the need to have the patient's consent to allow them to complain. This was particularly difficult when they had witnessed the poor treatment when visiting their loved one, or where they themselves felt like they had been treated badly by staff. As can be seen in the extracts below, some nurse patients refused to allow their nurse-family member to speak up and raise concerns directly with staff while they were still in hospital.

For example, when Gillian's (P6) partner (who is also a nurse) was still in hospital she did not want Gillian (P6) to raise concerns about her treatment:

“She was seeing things as well and then goes, *shut up and don't say a word*' and you feel as if you've held back from saying *'no, actually, I don't think you should be doing that'* or *'why are you doing this?'*”

(Gillian: P6)

Following her partner's discharge, Gillian (P6) wanted to complain to the hospital in writing. She had thought that now her partner had been discharged she would be willing to let Gillian (P6) complain.

"I had the email all typed out ready to go but [partner] is in senior management and she said, '*you can't put this complaint in without my permission and I don't give you my permission*' She wanted to forget it which is understandable in a way. In a way, what's done is done, but I really wanted to say, '*there are things I saw and [partner] experienced that you did wrong*'. It was disappointing and quite worrying actually and I wish [partner] had given me her permission because it was a very measured email".

(Gillian: P6)

This links to the subtheme *blurred boundaries* where nurse relatives were sometimes expected by family members to act in their nurse rather than simply their relative role. However, when it came to speaking up, the nurse relatives were often prevented from acting in an advocacy role or from complaining.

When others were told they needed the patient's consent to complain, they made the decision not to pursue their complaint because they did not want to add further to their relatives' distress, particularly at a time of bereavement.

"I made a complaint to the hospital about the consultant's actions and I was sent a letter back saying that as I wasn't the next of kin they couldn't pursue the complaint and it would only be if her [sister] partner agreed and I couldn't possibly ask him".

(Pat: P9)

"Then it was like *we'll have to get your wife's date of birth and more information*'. I felt like I was kind of dragging her into something knowing that she wouldn't have wanted to complain, so I put feedback and that was the last I heard".

(James: P4)

This was extremely difficult for participants on many levels. Not only were the nurse relatives coping with their own grief, they were supporting their family members. For each of these nurse relatives there was a feeling of sadness and frustration that they could not act on what they themselves had seen or witnessed. Having a poor experience was having an enduring

impact on their wellbeing and without the ability to complain, there was no explanation of why things went wrong and no resolution.

“I was really unhappy with things, but I had to let it go because it’s just destructive thinking about it all the time – she survived! “

(Gillian: P6)

Although still having a lasting impact, Gillian (P6) tried to put her experience into context; the main thing was that Gillian’s (P6) partner had survived.

Hear no evil

The second element in this theme links back to the theme *loss of trust*. Good complaint handling can restore trust in the relationship between the service user and provider. For this reason, The Patient Rights (Scotland) Act 2011 places a duty on NHS Boards to actively encourage all forms of feedback including complaints. However, the notion of NHS Boards welcoming feedback and handling complaints and concerns well was not the experience of many participants. For some participants this was strongly linked to *The Hidden Code* where resistance to hearing negative feedback was related to their nursing role. An example of this can be seen in the extract below from Julie (P7):

“Before I left, I did ask to speak to the ward manager....but when she came in she said, ‘*Everybody is up in arms because they think you are going to do nothing but complain about them*’ and I said ‘*no I’m not*’. I thought I would give her some positive feedback as well as negative”.

(Julie: P7)

Julie (P7) was in four different wards during her admission and her experience in this last ward was largely positive. However, in line with the stereotypes identified in Duke and Connor’s (2008) study, the underlying assumption was that Julie (P7) would complain because she is a nurse and she had already challenged staff she overheard talking about her outside the room. The ward manager’s opening statement ‘*everyone is up in arms*’ evokes an image of hostility or fear towards any negative feedback. Yet, when mistakes happen or services fail to meet expected standards, the power of a meaningful apology is well documented.

'An apology is more likely to resolve a complaint early than any other action you might take'.

(SPSO nd)

In the extract below Joan had a mixed experience when she met with a Senior Nurse Manager and the ward Senior Charge Nurse to discuss the failings in her father's care.

"I was incredibly upset and crying during speaking to them because I was having to relive the dreadful experience. The Senior Nurse was excellent. She'd obviously, I think she'd probably done some training and prepared an apology, so she was extremely good. When I said to the Senior Charge Nurse *'Look, I'm sorry, your ward is not safe'* she was extremely defensive, and the senior nurse intervened".

(Joan: P3)

For some participants, the lack of an acknowledgement and apology added to their anger and distress as evident in the extracts from John.

"Often an apology is all people want to hear, *'I'm sorry this has happened, it shouldn't have. I'm really sorry and this is what we are going to do'*. But there was none of that".

(John: P2)

As nurses, participants expected staff to exercise professional accountability.

Accountability is the principle that individuals and organisations are responsible for their actions and may be required to explain them to others.

(NMC nd. p3)

When staff did not acknowledge responsibility or provide an explanation there was further anger and disappointment as stated by John (P2), "I was disappointed and angry – angry for the lack of professional accountability for it", and similarly by Susan (P12), "There's something about the professionalism and people taking professional accountability for what wasn't done and trying to make it better". Here again there is a link, back to loss of trust. Not only has something gone wrong, but by not seeing staff be accountable, participants did not trust that anything would change as a result of their experience.

While some participants were familiar with the complaint's procedure, most were not. In accordance with the Patient Rights (Scotland) Act 2011 and the Regulations (2012) NHS

Boards must appoint a Complaints Manager and Complaints Officer. Part of their role is to provide expert advice to staff and patients about the complaints procedure and to support patients to decide what type of feedback they want to give. When he tried to complain, James (P4) not only felt let down by the service, but also by the Patient Experience Team.

“So, I wrote the email and they emailed back saying sorry about your experience but then asked me if I wanted it to be feedback or a complaint and at which point I kind of panicked a bit and thought ‘well I thought I’d already complained’. So, I put down ‘feedback and now I’m not sure if that’s right or not. Looking back on it, I feel a bit like, I feel like I was coerced into giving feedback when I wanted to make a complaint. Even though I think I think my email was in line with a complaint”.

(James: P4)

As illustrated in the extract above, the different forms of feedback outlined in the Patient Rights Act can be confusing for people. It was interesting that James used the word *coerced*. He felt pressurised into giving feedback rather than complaining. This could be linked to his own discomfort at complaining as outlined below:

“I think being a nurse kind of made me feel I could not [complain] but at the same time I felt quite guilty for doing it. You know, I just think, I guess you don’t want to get people into trouble you know, you don’t want to think about people and putting their jobs in jeopardy. I don’t know, it just feels like there’s a real kind of tension there”.

(James: P4)

However, it could also be reflective of the negative connotations often attached to the word ‘complaint’ and NHS Board’s desire to reduce the number of complaints by logging as feedback. What is also interesting in the extract above is James’ (P4) desire not to get staff into trouble and this is explored further in *speak no evil*.

One of the frustrations identified in the literature is of complainants not being able to get staff to listen to and understand their specific area of complaint. Often this is because lay people do not have the clinical knowledge to explain technical terms (Mulcahy, 2003). Although the participants had clinical knowledge, a few still had difficulty in getting staff to hear what they were saying. For example, April (p11) spoke of her frustration at getting staff to listen and to understand the nature of her complaint. Her mother in-law had fallen and as a result, been transferred to another hospital but staff failed to tell April (P11) and her husband that her

mother-in-law had been moved. It was this issue that was the subject of April's (P11) complaint, not the fall.

"It was more the fact that I didn't want to upset them [the nurses], but I wanted to make sure it didn't happen again. I didn't want it to be seen as a moan. I wanted them to try to see the difference. They were more interested in the fall, but I wasn't really concerned about the fall as it was her [mother-in law's] fault -she hadn't listened and she had capacity. So, I wasn't concerned about that. I was concerned about the lack of communication about her transfer to the acute hospital. It was more frustrating than anything else".

(April: P11)

Again, there was evidence of the dilemma between participants complaining and not wanting to get staff into trouble. They did not want to be seen as the stereotype of the complaining nurse.

Speak no evil

When exit is not possible, some people who receive a poor service will suffer in silence rather than voice, particularly if voice is perceived to have negative consequences. The extracts below illustrate some of the tensions and conflicts as the participants who chose to say nothing, or decided not to submit a written complaint, experienced in coming to their decision.

For some participants who had experienced rude or uncaring behaviours, the dilemma about whether to complain or not was whether it was a one off occurrence by a busy staff member that would lead to that staff member getting into trouble unjustifiably, or whether it was a pattern and the staff member would continue to be uncaring towards other patients. That tension was illustrated in the extract from Jennifer (P8) below:

"Do I really want to put a complaint in about the chap [staff nurse], you know, I don't know? But then there is a part of you '*is he like this all the time?*' you know, what if he's not taking on board what patients are saying to him? What else is going on there? You know, being a nurse you have a wee bit of power and you know, I've seen that being abused which is not a good thing with patients, it's not good."

(Jennifer: P8)

For others like Joan (P3), it was their insider knowledge of the culture prevented them from complaining. Although she had seen some improvements since raising concerns directly with

the senior nurse and charge nurse, she doubted whether this would be sustainable and whether proceeding further with a complaint would make a difference. In deciding whether to complain, the balance was between understanding the context in which her father received a low standard of care which she felt was due to systems level issues such as culture and staffing levels and understanding that the result of her complaint would be to the blame individuals at ward level rather than make system wide improvements.

“Rightly or wrongly, feeling a bit sorry for the nurses and the consequences [of my complaining] would probably not serve to address the big wrong issues in that hospital – that would probably land on disciplinary action for staff”.

(Joan: P3)

James (P4) was also concerned that in raising a complaint staff would get into trouble: ‘you have to blame and shame’.

For other participants, their insider knowledge of the system and the complaints process that prevented them from complaining.

“Whether they think you are just being ‘nit-picking’ because you do have insight. I honestly don’t know -because there’s my contrary attitude. I thought, ‘*Why didn’t I? Just why didn’t I?*’ But I don’t know, I just didn’t want to do it. I think it’s harder when you actually know because you realise the strengths and weaknesses of running a ward or department and then to suddenly have people coming in and complaining and you have to take people away from doing that. And would it change? Part of me thinks it wouldn’t change. No, I didn’t [complain] and I probably should have, but I didn’t and then - So, no, it’s hard, because I’ve often thought to myself “*Why didn’t you complain?*”. [...pause...] I was just being a coward”.

(Julie P7)

In the extract above, there is evidence that Julie (P7) was concerned that staff would think she was being unrealistic in her expectations. Her insider knowledge might have led to her compare her experience with the ‘gold standard’ and complain at a level of detail that lay people would not notice or not be concerned about.

Julie’s (P7) other concern related to her insider knowledge of the complaint’s procedure and the amount of time it can take to investigate and respond to complaints. From her managerial role, Julie (P7) was aware of the potential impact that her complaint would have on staff that

are already working short staffed and under pressure. On balance, like others, Julie (P7) decided that the benefit of complaining in terms of likely improvements to care did not outweigh the impact of complaining on staff. However, she continued to question her decision long after she had been discharged from hospital. This was the case for many participants, who unlike the stereotype complaining nurse patient or family member (Duke and Connor, 2008), were very conflicted about whether to complain. At the end of the extract, Julie described herself as a coward. This again speaks to the culture of the NHS not welcoming negative feedback. Why do you need to be brave to complain? For Julie (P7) this was more complicated because she worked in the hospital as a senior manager and was well known. She would not just be complaining about 'staff' but colleagues that she worked with.

"I wouldn't [complain] because of where I am in the organisation. My surname's unusual so people would immediately know it was me. I mean I'm not looking to further my career, goodness no, I don't want to go further than this, but [...pause...] I don't know...."

(Julie: P7)

This extract further hints at a culture of not welcoming negative feedback or complaints. It suggests that not only might complaining cause a detriment to care but could cause a detriment to Julie (P7) in her professional role.

For James (P4), the issue was not about his place of work but about having to use the service again and receiving less favourable treatment.

"The other thing about making a formal complaint is that we might have to use that service again next time. I think it would affect the kind of service you're getting in some way, where everyone is really fake nice to you".

(James: P4)

Some participants had considered complaining for some time after their experience: "The thought of writing a letter. I pondered for weeks. I think I stewed about it for a couple of weeks" (James P4). Jennifer (P8) also *pondered for weeks* about whether to complain as not all the care she received was poor.

"I'd seen feedback forms on one of the wards I was on and I went to go and look for them but I couldn't find them. If I had found them, I definitely would have, but the thought of coming, when I got home, sitting down and writing a letter, and I did ponder

for weeks you know. I wrote and thanked the pain nurses very much... because the pain aspect was terrifically well looked after”.

(Jennifer: P8)

Like other participants, the thought of having to put a complaint in writing was a barrier for Jennifer (P8), yet she had no trouble writing to the pain nurses to thank them for the excellent treatment she had received. It was perhaps not the act of writing that gave cause for concern but the act of complaining.

The thought of having to write a letter was an issue for other participants. In Susan’s case, it was not just about having to write a letter, she questioned the value of receiving a letter of response if she complained.

“I wanted to make them understand how it felt. It was like they were completely disinterested. And then I would have got a letter. So, I suppose that’s why I didn’t write at the time. I thought if I write a letter, I’ll get a letter. What does that even mean?”

(Susan: P8)

Here the issue was about the response. The loss of trust featured highly in Susan’s (P8) story. In the extract above she asked, ‘*What does that even mean?*’ which suggests it was not the written format of the complaint response that concerned Susan, but that she did not trust that her complaint would have been taken seriously, or that anything would improve as a result.

Being an insider was also an influencing factor in Joan’s (P3) decision not to take her complaint to the next stage. In her nurse role, she could see the impact of being short staffed.

“I think one of the disadvantages of being a nurse in that situation, I think I should have raised a complaint and I raised a concern [with the senior charge nurse] and I didn’t take it any further. I think in retrospect I should have raised a complaint because what I was seeing was so serious. I think I didn’t do that because I felt sorry for the nurses. Although I wasn’t overly impressed you could feel sorry for that charge nurse who was clearly working in a unit that didn’t have enough staff. But, there’s also part of you that’s, I think when you’re in that situation you don’t have a lot of energy”.

(Joan: P3)

Many participants, like Joan (P3), did not complain because they were still unwell, or just exhausted by the whole experience and glad to be home. This is illustrated in the extract below

where Jennifer (P8) was reflecting on why she didn't complain and what she would do if she was in a similar situation again

"I think I'd be a bit more assertive now, but there was that whole thing of me being so low, so tearful, which is very, very unlike me, and just absolutely dog tired, I mean like I was completely weary by that time and I just, so I don't know actually. I would like to think I would say something but, and then I suppose it's the whole thing when you've been through the experience and you're on the mend, you're feeling better and you think, you know, is it really worth it? And it wasn't anything major really....."

(Jennifer: P8)

In the extract above Jennifer (P8) ends by saying 'and it wasn't anything major really'. Not feeling that the issue is serious enough is another reason identified in the literature (Craigforth, 2006) why people don't complain and this was also stated by others: 'Yes there is the complaints procedure, but to me it's there for something much worse, I don't think it warrants a formal complaint- it warrants me speaking to the Charge Nurse, but not a formal complaint'

(April: P11).

Theme 4: Using my insight to make a difference

The theme *Using my insight to make a difference* refers to two constructs. The first relates directly to the research question and what, from their experience, participants thought could be done to make it easier for nurses who found themselves in a similar position to complain. The second refers to the lasting impact the experience had on the participants professionally and how some made changes to their own practice as a result of their experience.

Making it easier to complain

Central to the research question, this was the only theme that was derived from a direct question to participants. All participants wanted to tell the story about their experience and regardless of the length of time since their experience, narrated their stories in detail. In taking part in the study, most commented that they wanted to make a difference. As discussed in Chapter 4, during the pilot interviews there was a concern that the need for participants to tell their story was at the expense of keeping the interview focused on obtaining the data required to answer the research questions. One of the surprising findings was that even when asked directly '*What, if anything, would have made it easier for you to complain?*' most participants like April (P11) struggled to answer. 'I'm not sure what, if anything, would make it easier' (April: P11), and a few were unable to comment at all.

For some, their hesitancy may have related to their uncertainty about the complaints procedure and the definitions within the Patient Rights Act (2011) as illustrated when Shirley (05) commented, 'How do you make the distinction between a formal complaint and informal feedback?'

When Susan (P12) was asked if anything would have made it easier for her to complain she reflected on the incident when the senior nurse had visited her son. Susan recalled the anger she felt at that time as she suspected that the visit was to stop her complaining.

"I remember sitting thinking '*So, why are you here?*' You know, saying '*He looks ok! Right! 'So why did you come? What are you doing?'* So, I don't think anything would have made it easier at that point. When I did speak to her I didn't even think she was listening".

(Susan: P12)

Like the earlier extract from James (P4), Susan (P12) felt as if undue pressure was being put on her not to complain, but this time by senior staff that she worked with. Susan's (P12) comment '*I don't think anything would have made it easier at that point*' suggests that timing could play an important part in making a complaint. In this instance, in the moment, it was too soon, but as seen in the previous themes some participants 'pondered for weeks' before making their decision then decided that it was too late.

A few participants did make suggestions about how to make it easier to give feedback. Some had seen feedback forms in wards that they had previously worked in and suggested they should be made more widely available for all patients. Others, such as Gemma (P1) and Jennifer (P8), felt that there should be a more proactive approach:

"If we could find out when staff are in hospital. It would be difficult because of confidentiality but we could have an open invitation for staff to give feedback. Maybe to the patient complaints team?"

(Gemma: P1)

"you could put something on pay-slips or on social media to ask for feedback"

(Jennifer: P8)

Some participants suggested removing the negative connotations of the word complaint 'Not calling the complaints department complaints would help so feedback is not automatically considered a complaint' (Jennifer: P8)

A few participants commented that the reason they had wanted to participate in the study was because they regretted not complaining at the time of their experience. They thought that by taking part in the research and having the opportunity to tell their story, they might in some way still make a difference.

"There were a couple of experiences that I thought, not necessarily about making a complaint, but providing feedback, but I didn't, and so as soon as I saw your advert it kind of tied in with that and I thought maybe it's an opportunity to sort of – I realise it's not feeding back to the individuals involved in providing the care, but I'm afraid the business of life got in the way and I got to the point where my memory started to get a bit hazy about the details and I thought no, I'll leave it, which I'm a bit frustrated about .. it always helps improve matters if you can feed back and I didn't on that circumstance".

(Shirley: P5)

Having the opportunity to share their story was important to participants, but not just to share learning. They needed to be heard by someone who would listen to them.

Making a difference through my own practice

Although most participants had not given feedback or complained, they remained concerned that the consequence of them not doing so meant that the opportunity for others to learn from their experience was lost. A few described how they had used their experience to make changes to their own practice or had considered how they might share their experience to help others learn.

For some participants, their experience of poor care led them to reflect on their own practice and acknowledge that they did not always deliver the standard of care they delivered to others that they had expected for themselves.

"Being a nurse myself, I guess one thing I can imagine is that they have a very difficult job on that ward and maybe there's some kind of protective mechanism kicks in where you try to protect yourself from what's a really distressing job. I know from my own practice that there are times when I'm stressed and I'm not supported by my

management I do kind of back off my patients a bit more than I should, just to protect myself because I'm dealing with violence, aggression and distress".

(James: P4)

It was this insight that not only led participants to have empathy for the nurses looking after them, but also led them to seek to improve their own practice as can be seen in the extract from Susan (P12) below:

"I suppose it [the experience] makes you question yourself. '*Gosh do I behave like that as well?*'I wish the whole event, particularly that 4 hours of my life had never happened.... I just want to remove it from my memory, but I can't. And do you know, I think it's made me a better nurse because of it. I do think there's things I learned about nursing. I want to say, '*Just remember the privilege it is to be in that personal space of someone, to help them*'. They didn't choose to be here. We choose to be here as nurses. That's why I think it's a privilege and I didn't feel anybody thought it was a privilege to be there".

(Susan: P12)

Joan (P3) and Pat (P9) were both nurse educators but had very different stories about how their experiences had influenced their work.

"We will definitely be including more about shared care versus dumped care, and yes, we can use the scenario about a family, what support a family needs in a situation like I've described without saying '*this happened to me*'. Yes, you might have a bit of a unique perspective".

(Joan: P3)

In the extract below, Pat (P9) describes the impact various experiences of poor care, both as a patient and as a relative, had on her professional life. During a lecture she had referred to her experience of being a relative to illustrate a point.

"It did [impact] for a while. All of the stories did for a while and I think I was a bit of a loose cannon. I think it does affect...[pause]..something like having the experience of my sister, very close to me, and I can't actually remember what I said, but some sort of aside connection to the story and I thought I could get away with it and certainly with students, they know immediately, they know when it's something close to you and it

produces absolute silence in the lecture theatre. It's very effective, but its emotionally too hard and yes, I couldn't – I've learnt not to tap into it. I'm just too vulnerable I think".

(Pat: P9)

Both Joan (P3) and Pat (P9) recognised the power that their stories could bring to the learning environment but were also aware of the need to keep professional boundaries with students. While Joan (P3) was able to use her experience to influence indirectly through teaching programmes, for Pat (P9) the experience was too painful.

6.4 Conclusion

In conclusion, the duality of the nurse/patient and nurse relative role and their insider/outsider position were the threads running through the analysis. Those threads influenced how the nurse patients and nurse relatives assessed standards of care, how they experienced care, and whether they would complain when standards did not meet their expectations. Feelings such as disappointment and anger were not just directed at staff involved in their experience, but at the wider nursing profession. For some, the experience had a lasting impact on their wellbeing.

In the next chapter, I discuss the findings in relation to the aims of the study, the research questions and the literature.

Chapter 7: Discussion

7.1 Introduction

In this chapter I discuss the extent to which the findings from the final stage of the analysis in Chapter 5 fulfil the aims of this study and answer the research questions set out in Chapter 1. The aim of this research was to identify the circumstances in which it would be easier for nurses who find themselves in the role of ‘patient’ or ‘relative’ to complain when they have received or witnessed care or treatment they feel could be improved. The study was designed to answer the following two research questions:

1. What influences nurse patients’ or nurse relatives’ decisions about whether to complain about care or treatment they perceive to be poor?
2. What would make it easier for nurse patients or nurse relatives to complain about care or treatment they perceive to be poor?

While there were a few studies identified in the literature review that focused on how nurse patients and nurse family members experienced care, to my knowledge, this is the first study that set out to look at that experience through the lens of complaints management. As part of the discussion, I therefore consider the extent to which the findings from this research compare and contrast with the findings from the existing literature on nurse patient and nurse relative experience and where it makes a contribution to new knowledge. I then consider the strengths and limitations of the study and make recommendations for future policy, practice and research development.

7.2 Discussion of findings

As discussed in Chapter 1, a complaint is

“an expression of dissatisfaction by one or more members of the public about the organisation’s action or lack of action, or about the standard of service provided by or on behalf of an organisation”.

(Scottish Government and SPSO 2017).

While the data supports the idea that that the experience of nurses as patients and relatives provides a unique insight into care and experience that goes beyond that of lay people, what

the data also shows is that the picture is more complex than patients simply observing technical aspects of care and complaining when standards are not being met.

The final phase of the analysis resulted in four themes and three sub themes with *insider/outsider* as an overarching theme that ran through the whole analysis. From the themes and subthemes, there were 3 main factors evident in the data that influenced whether participants decided to complain. The first was the complex set of conditions involved in how participants decided the extent to which their ***experience met their expectations***. The second was about ***divided loyalties*** and whether they believed they could or should complain about their colleagues and a service they were part of. The third, was about the overall ***culture of fear*** not just of nurse patients and nurse relatives speaking up, but the fear that was evident in both participants and the staff caring for them.

With regard to what would make it easier for nurse patients and nurse relatives to complain, while participants were able to give some practical suggestions, the data found limited evidence that participants could identify circumstances that would make it easier at individual level. This suggests that ***change is required at leadership, policy, education, and practice level***, if we are to capture the rich experience of those with insider knowledge and use their insight and experience to improve quality.

What influences nurse patients' or nurse relatives' decisions about whether to complain about care or treatment they perceive to be poor?

Expectations versus Experience

In line with the evidence presented in the literature review, the nurse patients and nurse relatives in this study experienced care differently from lay people. Similar to the findings in Salmond's (2011) study, the patient-nurse and relative-nurse roles were completely intertwined. Participants moved (often within one sentence) back and forth along a continuum between their patient/relative and nurse role and their expectations and experience shifted depending on which point of the continuum they were at any given time.

Comparable to the findings from studies such as Salmond (2011), the data found that the multiple personas the nurse patients and nurse relatives occupied meant participants experienced additional stressors such as emotional turmoil, increased fear and anxiety, and feelings of powerlessness and loss of control. In addition to the findings presented in the literature, the data from this study found that the additional stressors were, as Gillian (P6) described, '*ramped up*' even further when participants experienced or observed care that at

best did not meet their expectations and at worst was unsafe. Witnessing poor practice or unsafe care led to an inability to 'switch off'. While Salmond (2011) found that family members hyper-vigilance over their loved one helped them maintain a sense of control, for the nurse relatives and nurse patients in this study, hypervigilance was often due to the anxiety caused by receiving or witnessing substandard care.

As with the findings from the literature review, analysis of the data from this study found that participants judged the quality of care they received or witnessed through their nursing lens (Cohen *et al.*, 2017; DeMarco *et al.*, 2004, Duke and Connor, 2008; Elayan and Ahmed, 2017; Picard *et al.*, 2004; Salmond, 2011; Zeitz, 1991). In doing so, participants drew on their clinical knowledge, their knowledge of professional standards, and their current or previous clinical experience. While in their literature review, Lines *et al.* (2015) found little evidence as to whether incidences of poor care related to the actions of health care professionals in the way they responded to nurse patients or nurse relatives, or whether it was that nurse patients and nurse relatives were better at identifying substandard care, the findings from this study suggest is that there was an element of both.

The Expectancy-Disconfirmation Model suggests that people with higher expectations are more likely to experience dissatisfaction (Van de Wall 2018; Zhang *et al.*, 2021). Some participants talked about expecting the *gold standard* and used clinical standards and *The Code* (2018) as their reference point for assessing standards and setting their expectations. However, when the gold standard was not achieved and substandard care was witnessed or received, as insiders, participants spoke about their experience in the context in which that care was being delivered. Drawing on their professional experience, many participants commented on staff shortages and the delegation of care to healthcare support workers. For some participants this caused significant tension. On one hand they expected care to be compliant with the professional standards they knew, but on the other, they questioned whether they were being 'too idealistic' or 'picky'.

For others, the expectations were less about the technical aspects of care but about being treated with compassion and care. Here participants often drew on *The Code* (NMC, 2018) to articulate the values and behaviours they expected to see. However, drawing on personal experience, some participants such as James (P4) and Susan (P12) spoke of occasions when their own practice had not met the gold standard, for example when James had avoided difficult relatives. Again, setting their experience in context was a factor that made it difficult to decide what standard of care they should expect. For others, such as Gillian (P6) there was

no excuse for staff being uncaring and this drove her desire to complain – she was only prevented from doing so by her partner refusing to give consent.

Blurred boundaries and role ambiguity led to confused expectations of the amount of involvement that nurse relatives were expected to have in their loved ones' care. From the literature, *'being let in'* and included as part of the care team was an important factor in reducing anxiety and fear (Salmond, 2011 and DeMarco *et al.*, 2004). The data in this study showed that while participants expected to be involved in communication about care and treatment, some felt that staff expected too much from them and that they were left to carry out often inappropriate levels of personal care. As Joan (P3) described, *'it was a complete abdication of care'*. For some, 'being involved' included taking on the role of translator for other family members and they were happy to take on that role, but for others, there was additional turmoil as they tried to hold their own anxiety while filtering information for family members.

Another influencing factor as to whether participants would complain was not knowing whether the cause of the dissatisfaction was serious enough. Some participants found it difficult to assess whether their experience justified a 'formal complaint'. Again, not thinking the complaint is serious enough is a common reason for patients not voicing concern (Craigforth, 2009). While they felt the level of concern might not be serious enough, some like Jennifer (P8) also questioned 'but what if it happened more than once?'. Back in their insider role, some participants spoke of how low-level complaints that occur frequently can have a significant impact on the quality of care or might reveal a performance issue with a staff member.

As can be seen, the data from this study found a complex set of conditions that determined the level and quality of care the nurse patients and nurse relatives thought they should expect. What the findings also suggest is that the additional stressors experienced may mean that nurse patients and nurse relatives have a poorer experience of care than lay people at the outset. There were tensions between knowing the 'gold standard', knowing what a 'reasonable standard' was, knowing what was unsafe, and what standard of care was possible for colleagues to deliver. For many participants, these complexities impacted on whether they felt they had reasonable grounds to complain.

Divided loyalties

One of the biggest influencing factors as to whether nurse patients and nurse relatives would complain was their relationship with family members, staff, the profession and the wider health service.

Relationships with family members influenced whether nurse relatives would complain in two ways. Firstly, for some nurse relatives, their family member refused to give consent to allow them to complain, or in Pat's (P9) case to advocate on behalf of their relative. For others, in the role of protector, it was too difficult to ask for consent during a time of grieving and bereavement. Not being allowed to complain had a lasting impact on participants with some such as Gillian (P6) still feeling regret at the time of interview, but resigned to the fact that they had to 'let it go' because their relative had survived.

For most participants, being on the receiving end or witnessing the poor care of their loved one, led to deep feelings of disappointment, shame and loss of trust. However, for many participants, despite feeling let down, particularly by the nursing profession, there was still an underlying feeling of loyalty. For example, when Joan (P3) found herself observing a situation that she thought was unsafe, she was conflicted between her role as a daughter and her role as a registrant; as a professional she questioned whether she should be raising the situation with the NMC, but at the same time she felt sorry for the staff.

Linked to feelings of empathy for staff, was some participant's desire to be seen to be good and helpful. While Salmond's (2011) study found that nurses tried to foster relationships with staff to access information about their loved one, as discussed in the findings, participants in this study wanted to be seen to be 'good' by staff. This meant helping 'colleagues' when they were short staffed, but also, in line with the stereotype of the complaining nurse in Duke and Connor's (2008) study, not wanting to be seen as the moaning relative (McCreddie et al., 2018), and not complaining for fear of causing further detriment to their family member (Craigforth, 2006).

While it has been identified that many people do not complain because they do not want to get staff into trouble (Brüggemann, 2017; Craigforth, 2006), for the participants in this study, it again went beyond the idea of reporting 'staff' to reporting 'colleagues'. A number spoke of the 'blame culture' that they worked in, and I discuss this further in the next section, but what was also interesting was their comments on understanding the length of time it can take to investigate complaints and not wanting to increase the burden on an already stretched workforce.

The data found that many participants in this study pondered for weeks over whether to complain about their experience and at the time of interview some were still torn while others regretted not complaining. Again, the insider outsider conflict was apparent for many, between complaining as outsiders and complaining about a service, standards and culture that they were part of as insiders.

Culture of fear and reluctance to listen

In Chapter 1, the landscape of successive reports and inquiries described a culture of fear surrounding complaints and a reluctance of the NHS to welcome feedback and to listen (Department of Health, 2013, Craigforth, 2006; Scottish Health Council, 2014). The data found that a culture of fear and reluctance to listen was still evident in the narratives of participants in this study, with some reporting in line with the complaints literature, that they believed complaining was a waste of time because it wouldn't make any difference (Clwyd and Hart, 2013; Craigforth, 2009; Scottish Health Council, 2014).

Many participants spoke of a 'blame culture' and of fear. What was interesting, was that the fear experienced by participants in this study was not just about complaining as patients or relatives, it was deeply rooted in their nursing role. For the majority, the fear relating to their role was apparent even when they, or their loved one, were being cared for outwith their place of work and they had no personal relationship with staff. While Duke and Connor (2008) and Salmond (2011) found evidence that nurse patients and nurse relatives had a better experience of care when they were admitted to their place of work, this was not the case for Julie and Susan who had the increased concern about confidentiality and the impact complaining would have on their jobs.

Most participants were fearful of staff's reaction to finding out they were nurses and took active steps to conceal the fact. When they were found out, some participants like those in Salmond's (2011) study, modified their behaviour to make it less intimidating for staff looking after them. For others, in line with Dukes and Connor's (2008) findings, there were times when staffs' fear of looking after nurse patients, or communicating with nurse relatives, meant that participants were avoided. This avoidance not only added to their anxiety and poor experience but prevented staff from having the opportunity to resolve concerns early in line with the Model Complaints Handling Procedure (SPSO, 2017).

While participants in the studies by DeMarco *et al.*, (2004) and Salmond (2011) reported that they recognised staff could feel intimidated looking after other nurses, what was not evident

in the literature was the reason *why* this should be the case. Nurses observe each other's practice all the time, so a significant issue for consideration is why is it so different when the nurse is a patient or relative. Some participants reflected on the culture within their own practice, admitting that they were fearful of complaints and having to make sure everything was *done the way it should be* when looking after other nurses.

There were a few exceptions to participants being fearful and concealing their nursing role. For example, when participants such as Pat, who initially tried to conceal her role as a nurse teacher, deliberately disclosed that she was a nurse in order to have her concerns heard, and Gemma used her nursing position to put pressure on her mother's GP.

Interestingly, despite the culture of staff being intimidated and participants being avoided, some participants did speak directly to clinical staff about their concerns. Evidence from the literature and from national reports found that feedback to NHS staff about standards of care was not always welcome (Cohen *et al.*, 2021; Salmond, 2011; Scottish Health Council, 2014), with Salmond (2011) reporting that participants were reminded that they were in a family member – not a nursing role. However, the findings in this study were mixed with some staff responding positively, such as the senior nurse who met with Joan about her father's care, while others were immediately defensive.

As seen in the introduction, a culture of fear and an unwillingness to listen to feedback has reigned in the NHS almost since its inception. Successive governments have responded to inquiries and scandal by changing policy and legislation, and more recently there have been calls for the removal of the culture of fear (Department of Health, 2013; Scottish Health Council 2014). However, the evidence in the findings suggests that fear still remains prevalent and for the nurse patients and nurse relatives, this was intensified because of their nursing role. I expand on culture further in the following section.

What would make it easier for nurse patients or nurse relatives to complain about care or treatment they perceive to be poor?

In common with the findings from the literature review, participants in this study offered a rich insight into the experience of being a patient or relative, often commenting on technical aspects of care, systems issues and culture that would be beyond lay people in the same position. This was evident, for example, in Julie's detailed description of infection control procedures not being met at a time when she was critically ill in the Emergency Department. If services are to tap into that knowledge and experience for learning and to improve the quality

of care, it is essential that nurse patients and nurse relatives can complain without fear of a detriment to their care or working life.

Unlike Elayan *et al.* (2017) who found that nurse patients were uncomfortable verbalising unpleasant experiences, the nurse patients and nurse relatives in this study were very anxious to tell their story when interviewed. However, they were less confident in discussing what would have made it easier for them to complain to the NHS. Initially, this was a cause for concern because it was fundamental to the research question and the participants were struggling to answer even when asked directly. However, through the analysis I came to realise that what can appear to be a lack of data is in itself data. What became evident during the analysis was that making it easier to complain went beyond simply improving individuals' knowledge and understanding of the complaint's procedure. From the analysis, there were three factors that would make it easier for nurse patients and nurse relatives to complain;

- Person centred practice
- Removing the fear and listening
- The complaints process- restoration of trust and wellbeing

Person Centred Practice

From the analysis, the loss of trust was felt deeply by participants, and it went beyond the poor care experienced to loss of trust in the profession and the wider service. Trust is the cornerstone in any therapeutic relationship and is also fundamental to dealing with complaints effectively.

The findings in this study are supported by the evidence in literature, which is consistent in reporting that the experience of nurse patients and nurse relatives is different from that of lay people, with role conflict, heightened anxiety and competing expectations being common. For this reason, staff looking after nurse patients and nurse relatives need to build trust through adopting a person-centred approach that takes into consideration the unique way individual nurse patients and nurse relatives experience care. This means not making assumptions about the level of involvement expected or the level of clinical knowledge, but asking individuals how involved they want to be and what level of information they need (DeMarco *et al.*, 2004; Duke and Connor, 2008; Salmond, 2011). It also means staff having the confidence to find out what is worrying nurse relatives and nurse patients and rather than avoidance, to acknowledge their dual role and be present in providing support (Duke and Connor, 2008).

There needs to be greater understanding that the very people that could provide rich insight into the quality of services have additional barriers to complaining, such as struggling with role identity, professional shame and fear.

Removing the fear and listening

The evidence from the data suggests that for nurse patients and nurse relatives to feel confident in complaining, there needs to be trust that complaining will not cause a detriment to their future care or to their employment and the staff looking after them need to be confident that they will not be blamed if mistakes are made.

In Chapter 1, presenting the history of NHS complaints management as a chronology showed a long history of the reluctance of the NHS to listen to staff and the public raising concerns about poor standards and patient safety. The publicity surrounding major scandals did not just highlight the failings and poor standards, but the vilification of staff and members of the public who raised concerns. As Brennan (2013) highlights, such adverse publicity itself can invoke fear in organisations and individuals, further deepening the culture of fear of speaking up. Many of the more recent failings are within the living memory of staff working in the NHS today.

The response of successive governments to major failings, until recently, focused largely on changing policy, procedure and legislation. However, since the failings in Mid- Staffordshire, there is a greater understanding that a culture of fear presents a significant risk to patient safety and quality improvement there have been calls to drive out the culture of fear from the NHS (Clwyd and Hart 2013; Department of Health, 2013; Scottish Health Council, 2014). The Scottish Government review of the Model Complaints Handling Procedure (Bonello, 2019) found that

'The CHP implementation has been positive for the Boards with progress in the culture around complaints, embracing learning and steadily moving away from the blame culture'.

Bonello (2019)

However, the findings from this study suggest that for nurse patients and nurse relatives, there is still some way to go. As discussed, there was an additional layer of fear for many of the participants in this study as a result of their insider knowledge of their care and treatment that was exacerbated when that care or treatment was found to be poor. Similar to the findings in the literature (Duke and Connor, 2008; Zeitz, 1999), what also came through strongly was how intimidating and daunting it was for staff looking after other nurses and the resultant

avoidance behaviour experienced at a time when the participants were at their most vulnerable and needed most support.

The Code (NMC, 2018) was referred to by a number of participants throughout the interviews and analysis of the data suggests that in treating nurse patients and nurse relatives differently, the principles and values of The Code (NMC 2018) are not always upheld when the nursing profession looks after its own. With a greater understanding of the fear and vulnerabilities many nurse patients and nurse relatives experience, and understanding that the stereotypes of the nurse patients and nurse relatives as 'complaining' are largely unfounded (Duke and Connor, 2008), staff may be less fearful in approaching and engaging with nurses both in the delivery of person centred care and in actively soliciting feedback.

The complaints process

All participants in this study expressed a level of dissatisfaction with the care they had received or witnessed that would have fitted with the definition of a complaint. However, despite the introduction of the Patient Rights (Scotland) Act (2011) and recent focus by the Scottish Government, SPSO and NHS boards on improving complaints management, few participants knew or understood the definitions of feedback, comments, concerns and complaints. The majority spoke of giving 'informal feedback' or making a 'formal complaint' which they believed had to be in writing.

Identified as a recommendation in *Listening and Learning* (Scottish Health Council, 2014), the Model Complaints Handling Procedure (2017) places a duty on NHS Boards to resolve complaints early and for frontline staff to have ownership. However, the avoidance and lack of engagement of staff with participants in this study meant that opportunities to listen and put things right at an early stage were often lost.

It is inevitable that the quality of health services will sometimes fall below that expected and that mistakes will occur. When this happens, good complaint handling can restore trust and put things right. Participants who spoke directly with clinical staff were met with a mixed response. Despite apology being identified by the SPSO (2021) as *more likely to resolve a complaint than any other action*, and The Apologies (Scotland) Act 2016, for some participants, the lack of apology and acknowledgement added to their anger and distress. Participants were not looking for someone to blame; they understood the context that staff were working in, but what they did want was for staff to be accountable and acknowledge where there had been failings in care.

Having the opportunity to share their story as part of the research was important to participants. They needed to be heard by someone who would listen to them and understand that they experienced care differently. Welcoming feedback from nurse patients and nurse relatives, is not only important in terms of the poor practice experienced but needs to find a way to restore trust and confidence in the nursing profession and sometimes with the nurse patients' and nurse relatives' employer.

Feedback from some participants at the end of the interview provided evidence that being able to tell their story in an environment where they felt safe to do so was cathartic and had a positive impact on them. Not everyone who has a poor experience of care or treatment will want to complain, even if support is offered to do so. It is important that that other forms of feedback are available to nurse patients and nurse relatives that recognise their unique experiences, the additional stressors and barriers to complaining are considered. What was evident in the data was the lasting negative impact that failure to listen had on the wellbeing of some participants.

7.3 Limitations

This small-scale study was undertaken as part of a part-time clinical doctorate programme. As such, there were expected limitations in terms of resource and time available that were accounted for in the study design. However, one of the unforeseen limitations of this study was that it took longer than anticipated to complete. This meant that the data collection was completed 2 years before the final analysis. While updating the literature review in January 2022 found that the topic is still relevant and under researched, there is a risk that any changes in policy and practice during the course of the study would impact on the currency of the findings.

Methodological limitations

One of the limitations was the small sample size. While the data collected was rich and contained a range of views, a larger sample may have improved the findings by widening the range of differing views. Within the sample, 5 out of the 12 participants were working in education or clinical research. This may have been because the study was mainly advertised through the RCN bulletin. Wider advertisement may have led to a more diverse sample. However, there was an additional limitation in that regard with one NHS Board refusing permission for the study to be advertised within the Board area.

Data collection was through semi-structured interviews. The robustness of the data captured is dependent on the skill of the interviewer. Although I had extensive experience undertaking interviews in other settings, I was inexperienced in research interviewing. While the pilot interviews, feedback from supervision and reflexivity improved my interview technique, for example, learning when I might be asking leading questions, a more experienced qualitative interviewer may have identified times when deeper probing or timely follow up questions would have led to fuller answers and generated richer data.

While subjectivity is viewed as a strength in reflexive thematic analysis, I had to be aware of the risk of trying to make the data fit the questions. Discussion of the themes as they were developing through supervision and reflexive journaling supported the rigour of the analysis.

Scope

Although some had tried, none of the participants in the study had their dissatisfaction resolved under the complaint's procedure. It may have added additional depth and perspective to explore the outcomes for those who had been through the complaints process and what factors had enabled them to do so.

For pragmatic reasons, because all interviews were face to face, the study was limited to the 5 Health Boards situated within a 50-mile radius of Lothian. This could have impacted on the diversity of the sample and range of experiences.

Value of the study

Despite the limitations, this study provides a valuable contribution to the existing small body of knowledge about the experience of nurses who find themselves in the role of patient or relative. It has also gone some way to addressing a gap in the literature by presenting new knowledge relating to the circumstances in which it would be easier for nurse patient and nurse relatives to complain when they experience care they perceive to be poor.

7.4 Conclusion

In conclusion, the findings from this study support the findings of earlier studies that explored the experiences of nurses as patients of family members. In addition, this study adds to the existing body of knowledge by examining that experience through the lens of complaints management.

The study found three main factors that influenced whether participants would complain: the extent to which their experience met their expectations; divided loyalties; and a culture of fear.

To make it easier for nurse patients and nurse relatives to complain, change is required at different levels including policy, leadership, education and practice level. This forms the basis of the recommendations presented in the following chapter.

Chapter 8: Recommendations, final reflections and conclusions

8.1 Introduction

In this chapter I make recommendations for policy, leadership, practice, and education, following which, I present a plan for the dissemination of this study and identify opportunities for further research. Finally, I present my personal reflections of undertaking this study and draw final conclusions.

8.2 Recommendations

The findings from this study have implications for all levels of healthcare, from Scottish Government, organisations such as Health Boards, Health and Social Care Partnerships, and Higher Education Institutes to front line practitioners. While the focus of the recommendations is Scotland, the literature review presented in Chapter 2 identified relevant studies from around the world suggesting that the recommendations presented may have international relevance. In addition, while the participants in this study were nurses, the recommendations may also have relevance to other health and social care practitioners and to the wider public.

Policy and Culture

It is sadly inevitable in healthcare that there are occasions when mistakes happen or care falls below the standard expected. It is essential that in those circumstances nurse patients and nurse relatives can complain. However, this study found that the definitions “complain, concern, comment and feedback” (Patient Rights Act, 2011) were confusing, even to those with insider knowledge. For this reason, a wider enquiry into whether these definitions are meaningful to patients and their relatives should be considered.

Lessons from the history of complaints management presented in Chapter 1 indicate that recent changes to the approach to complaints management in Scotland are beginning to have a positive impact (Bonello, 2019). However, what is also evident is that making amendments to complaints legislation, policy and procedure alone is unlikely to lead to sustainable improvement in complaint handling. The findings from this study support that. In line with the recommendations presented by Berwick (Department of Health, 2013), policy development should continue to focus on welcoming complaints and other forms of feedback within the context of a **learning and improvement culture**. This will require effective leadership at all levels.

Leadership

Key to the successful improvement in managing complaints from nurse patients and nurse relatives, and from the wider population, will be a commitment of senior leaders in government and in healthcare organisations to work towards a culture that drives out fear and focuses on learning and improving quality. This needs to go beyond legislation and policy describing culture change, to the enactment of leadership behaviours at all levels that support staff when mistakes are made or when wider systems pressures result in sub-optimal care.

Senior leaders should consider strategies that encourage and empower nurses and other healthcare professionals to give feedback using a range of different methods, and involve them, where appropriate, in the development of improvement plans and sharing learning so that they can be assured that their feedback has made a difference.

Senior leaders should support practitioners through training and development to be confident in looking after other healthcare professionals and to pro-actively engage with rather than avoid nurse patients and nurse relatives. Staff should be actively supported to encourage nurse patients and nurse relatives to question care and give feedback or complain without fear of consequences to future care when that feedback is highlighting poor practice or patient safety issues.

Consideration should be given to the availability of support such as counselling services for staff who have been patients or relatives.

Practice

The most significant implication for practice is that practitioners need to understand the unique way that care is experienced by nurse patients and nurse relatives, including the potential additional fear and stressors that occur as a result of balancing multiple roles, and the impact that having clinical knowledge has on anticipating the worst-case scenario. The care of nurse patients and nurse relatives needs to be truly person centred and focussed on the whole family.

Therapeutic relationships are built on trust and key to building trust is effective communication. While nurse patients and nurse relatives have clinical knowledge, their knowledge will vary

depending on specialty and experience. It is therefore essential that staff enquire as to what level of information they want and need, as well as how involved nurse relatives, with consent of the patient, expect to be involved in decisions about and delivery of their loved one's care. Staff should never assume that nurse relatives want to be involved in the direct care of their family member. Again, sensitive enquiry is key.

Staff need to understand the lasting trauma a poor experience of care can have on patients and relatives, particularly those with insider knowledge who are balancing multiple roles. The impact of avoiding nurse patients and nurse relatives and being defensive in the face of receiving a complaint from them only exacerbates that trauma. As discussed, often frontline staff have the first opportunity to resolve complaints early. It is essential therefore that staff understand the power of transparency and offer a meaningful apology that acknowledges where things have gone wrong. Only by learning to adopt an approach that is welcoming of feedback can health care organisations tap into the experience of nurse patients and nurse relatives to learn from their unique insight.

Education

Evidence from the literature and from this study suggests that nurses are often ill-prepared to look after other nurses. As part of the education on person centred practice, consideration should be given as part of the curriculum for undergraduate nurses to prepare them for looking after nurses and other healthcare professionals. The use of nurse patient /nurse relative stories would give students insight into the unique way that nurses experience care when they are patients or relatives while giving the opportunity for nurse patients and nurse relatives to be heard and contribute to making a difference.

In addition to undergraduate education, the education needs of frontline staff need to be considered. The inclusion of how to support those nurses who are both looking after other nurses could be incorporated into all existing education/ training regarding person/ family centred practice and complaints management.

What was also evident in the findings from the literature and this study was that nurses are often not prepared when they find themselves in the role of patient or relative. In addition to preparing staff to look after other nurses, consideration should be given to how we prepare nurses for the additional stressors being in a dual role can bring, possibly through sharing the experiences of those who have been in that position.

NHS Board Patient Experience Teams are expert in complaints policy and procedure and support staff to manage feedback and complaints. Consideration should also be given to educating Patient Experience Teams about the unique way nurse patients and nurse relatives experience care and the additional barriers they face to complaining. This would enable them to better support nurse patients and nurse relatives to give feedback or complain and support staff who are being complained against.

8.3 Dissemination and Implementation of Recommendations

One of the most important elements of the Clinical Doctorate Programme is that any research undertaken should have an impact on practice. One of the main ways to influence the implementation of research is through wide dissemination. However, Brownson et al (2018) suggest that passive dissemination of research does little to reduce the research - practice gap because the uptake of recommendations does not happen spontaneously.

In developing a plan for dissemination, firstly, it is important to determine who the target audience(s) for the research are. Secondly, it is important to consider a wide range of methods, mediums and approaches, particularly where the audiences are diverse. As this study is likely to be of interest to policy makers, senior leaders and frontline practitioners, in developing a plan for dissemination, it was important to take into consideration which approach would be most appropriate for each audience.

Table 12 Dissemination Plan

The following outlines the plan for dissemination of the research findings. It includes the target audience, the method of dissemination and planned date of delivery. The plan is not exhaustive as it is anticipated that further opportunities not yet identified may arise.

Target Audience	Method of dissemination	Planned date
Policy makers		
Chief Nursing Officer for Scotland	Face to face meeting	October 2022 (complete)
5 Nations Chief Nursing Officer's Meeting	Face to face (Teams) meeting/ presentation	March 2023
Scottish Executive Nurse Directors Group	Face to face (Teams) meeting/presentation	March 2023
National Complaints Personnel Association Scotland	Face to face (Teams) meeting/presentation	April 2023
Nurse Advisor, SPSO	Face to face meeting	February 2023
Local NHS Board / Health and Social Care Partnership		

Executive and senior leadership teams	Face to face meeting/presentation	October 2022
Nurse Director's Meeting	Face to face meeting/presentation	November 2022
Local professional / QI/ Research forums	Presentation and interactive workshops	2022-2023
Local patient experience teams	Presentation and interactive workshops	2022-2023
Wider Dissemination		
Nursing and health/ social care practitioners/ Researchers/ Educators	Publication of research in peer reviewed journal	(1 st Draft complete) Submission Autumn 2023
Nursing and health/ social care practitioners/ Researchers/ Educators	Conference Presentations / Seminars	To be arranged
Nursing and health/ social care practitioners/ Researchers/ Educators	Poster Presentations	Ready for Summer 2023
Nursing and health/ social care practitioners/ Researchers/ Educators	Royal College of Nursing	Summer 2023
All groups including general public	Social media: Linked in Twitter Research Gate	On -going from 2023

Evaluating the impact of research dissemination

Another important factor in the dissemination of research is evaluating its impact on practice (Ross Hellauer et al., 2020). While doing this on a large-scale is beyond the scope of many single researchers, it is important to solicit feedback, for example, from conference/workshop participants through conference/ workshop feedback forms, looking at citations from publications, and identification of any policy and practice changes.

Further research

A study to explore the experience of nurses looking after other nurses would complement this study by providing greater insight into why it is so difficult and why nurses avoid nurse patients and nurse relatives.

While this study examined the experience of nurse patients and nurse relatives through the lens of poor experience and complaints management, it is important to stress that nurse patients and nurse relatives will experience excellent care. It is equally important that learning

is shared when things go well as when mistakes are made. Research into the positive experiences of nurse patients and nurse relatives would also compliment this study.

8.3 Final Reflections and Conclusions

Undertaking this study has been an incredible journey of learning - not just about my chosen research subject but about the whole research process. At times it was frustrating and at others it just felt difficult, especially during the analysis when at times nothing seemed to be working. Then there was the experience of joy during a 'lightbulb moment' when a piece of the analysis fell into place. I have been mentally challenged in ways I never thought possible. There were times when the testament of participants was harrowing to listen to. One of the most important lessons, particularly during the analysis phase and being immersed in the data, was knowing when to step back and take care of myself.

In conclusion, this study builds on the existing, limited body of knowledge about the unique way nurse patients and nurse relatives experience care. The findings also contribute new knowledge by addressing an identified gap in the literature about how the multifactorial way care was observed, judged and experienced by nurse patients and nurse relatives influenced their decisions to complain when they received or witnessed care that did not meet their expectations, and points to the changes in leadership, policy, practice and education required to make it easier for them to do so.

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INTERVIEW TOPIC GUIDE

Research Questions

What influences nurse patient or nurse relatives' decisions on whether to complain about care or treatment they perceive to be poor?

What would make it easier for nurse patients or nurse relatives to complain about care or treatment they perceive to be poor?

1. Introduction

- Introductions and thank you for agreeing to take part.
- Go over Participant Information Sheet
- Give assurance that all information will be anonymised
- Transcription will be to an external source and will be confidential – If not happy the researcher will transcribe – note on consent form.
- Can pause or stop the interview at any time.
- Obtain content.

2. Initial Questions.

- Can I first of all ask you how long you have been qualified as a nurse?
 - What area/specialty do you work in?
 - In what area/ specialty were you a patient/ relative?
-

3. Experience of being a patient/ relative and describing the 'poor practice'

Nurse Patient

- Can you tell me about your experience of being a patient?
 - The following questions will depend on the answer given:
 - What was it about the practice that was poor?
 - When you experienced [*reflect back poor practice as described*] how did you feel?
 - How did being a nurse affect your experience of being a patient?
 - Did you feel staff treated you differently because you are a nurse? In what way was that?

- How did this experience affect you personally? Professionally?

Probe until nothing further to add for example, 'You mentioned x, can you tell me a bit more about that?'

Nurse Relative

- Can you tell me about your experience in relation to your relative's [*name*] care and treatment?

The following questions will depend on the answer given:

- What was it about the practice that was poor?
- How did being a nurse affect your experience of visiting/ accompanying your relative?
- What were your relative's [*name*] expectations of you as a 'nurse/relative'?
- Did you feel staff treated you differently because you are a nurse? In what way was that?
- When you experienced [*reflect back poor practice as described*] how did you feel?
- How did this experience affect you personally? Professionally?

4. Deciding whether or not to complain or raise a concern

Chose not to complain:

- Why did you choose not tell staff about your experience at the time?
- Did you consider making a complaint?
 - Why did you decide not to?

Probe, for example, 'were there any other reasons?'

or 'what made you think that?'

- How do you feel about not telling staff about what had happened?
 - Personally/ professionally?
- Did you speak to any colleagues/friends or family about the problem?
- What, if any, support was available to you?

- If you were to be in the same position again, do you think you would make the same decision?
 - If no – what would you do differently?
 - What would have made you more likely to complain?

Raised a concern:

- What made you decide to tell staff about your concerns?
- At what point did you raise the concern? [*e.g. during hospital stay/ post discharge*]
 - What made you decide to do it at the time?
 - OR Why did you decide to wait until you [*your relative*] had been discharged?
- Did you consider making a complaint?
 - If yes, why did you not?
- How did staff deal with your concern?
- What did you expect to happen as a result of raising your concern?
- How did you feel about raising the concern?
 - In what way did being a nurse affect how you felt?
- [*If during hospital stay*] Were you [*or your relative*] treated any differently by staff as a result of you raising the concern?
 - If yes, in what way were you treated differently?
- If you were to be in the same position again, do you think you would make the same decision?

Made a complaint

- What made you decide to complain?
- Did you raise concerns with staff before you decided to complain?
 - If yes, how did staff deal with your concerns?
 - If no, why did you decide not to speak to anyone first?
- What were your expectations in making a complaint?
 - What did you want the outcome to be?
- How did staff deal with your complaint?
 - Can you tell me a bit about their communication with you?

- How adequate was the explanation you were given about what happened?
 - Do you feel your complaint has been resolved?
 - If you were to be in the same position again, do you think you would make the same decision?
 - What would have prevented you from having to make a complaint?
-
-

5. Impact of the decision to complain or not

- How has your decision affected you
 - Personally?
 - Professionally
 - [If complained] Have there been any ‘consequences’ for you or your relative as a result of your complaint?
 - [*If patient/relative out with own ward/ department*] Have you discussed your experience with colleagues you work with?
 - What impact has raising a concern had on relationships with them?
 - OR why did you decide not to share your experience with those you work with?
-
-

6. Using the experience to make a difference

[complaint/concern only] Do you know if practice changed as a result of you raising a concern/ complaining?

- In what way did it change?
 - [All] How has your experience affected your own practice as a nurse?
 - Have you used your experience to try to change the practice of your colleagues?
 - In what way?
-
-

7. Making it easier

- What would have made it easier for you to give feedback or raise concerns at the time of the incident?

- What do you think needs to change for improvements to happen as a result of feedback from staff in the position of patient/relative?

8. And finally.....

- Is there anything else you would like to tell me?

9. Close down.

Thank you very much for taking the time to speak with me.

Ask for example ... do you have anything nice planned for the rest of the day?

Note any further important point



Research Study Advertisement

VOLUNTEERS NEEDED

For a research study on

Using the experience of 'nurse patients' and 'nurse relatives,' as informed consumers of healthcare, to make service improvements: A qualitative study.

I am currently undertaking a Clinical Doctorate (Nursing) at the University of Stirling. I am required to undertake a project as part of the course and am looking for volunteers to take part in the above study.

The aim of the study is to identify the circumstances in which it would be easier for nurses who find themselves in the role of 'patient' or 'relative' to give feedback when they have received or witnessed care or treatment which they feel could be improved.

I would like to interview **Registered Nurses** who have been in hospital either as a patient, or have visited a relative in hospital, and who have received or witnessed care that they feel could be improved. I would like to speak with nurses who raised concerns or complained as a result of their experience as well as those who gave no feedback.

The interview will last approximately 1 hour and can either be conducted in your home or an alternative location of your choice.

If this is you and you would like to consider taking part please contact me for further information at:

Contact Information

Jacqueline Macrae
Clinical Doctorate (Nursing) Student

Email Jacqueline.richardson@stir.ac.uk

Telephone: 07875201127 (work)

APPENDIX 3



UNIVERSITY OF
STIRLING

SCHOOL OF
NURSING, MIDWIFERY
AND HEALTH

PARTICIPANT INFORMATION SHEET 2

[nurse / patient relatives who have **NOT** made a complaint]

Researcher: Jacqueline J Macrae, Doctor of Nursing student, University of Stirling

Contact: Tel: 07875 201127

Email: Jacqueline.richardson@stir.ac.uk

Study Title: *Using the experience of 'nurse patients' and 'nurse relatives,' as informed consumers of healthcare, to make service improvements: A qualitative study.*

You are being invited to take part in a research project. Before you decide whether or not to take part, it is important for you to know what the research is about and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please contact me on the above telephone number or email address if anything is not clear, or if you would like more information, and take time to decide whether or not you wish to take part.

What is the purpose of the project?

I am undertaking a Doctor of Nursing Programme at University of Stirling and the research project is part of the programme.

We know from the little research that is available that certain groups in the population find it difficult to raise concerns or complain about their healthcare. From anecdotal evidence, and from a small number of studies, nurses who are patients or relatives may also find this difficult for a number of personal and professional reasons. Yet, as people with 'insider knowledge' of health care and how the systems work, the

feedback from nurse patient/ relatives could be an invaluable resource for Boards to improve the care and treatment for patients.

The purpose of the project is to identify the circumstances under which it would be possible for nurses who find themselves in the role of 'patient' or 'relative', within the NHS Board in which they are also employed, to give feedback when they have received or witnessed poor care or treatment, without causing detriment to their on-going employee/employer and colleague/colleague relationships.

Why have I been chosen?

The reason you have been chosen is because of your recent experience as a patient or relative in the NHS a colleague/ friend suggested that you might be willing to take part.

The aim is to recruit around 15 nurse patient/ relatives who have received (or witnessed) care or treatment they perceive to be poor in the NHS Board in which they are also employed as a registered nurse. The sample will be drawn from 5 NHS Boards across Scotland, and will include both nurses who chose to raise concerns or make a complaint and those who chose not to do so.

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part in the project. If you do decide to take part, you will be asked to sign a consent form. You can withdraw from the project **at any time**, and you do not have to give a reason for doing so.

What do I have to do if I take part?

If you decide to take part in the study, you should sign the consent form and return it to me in the stamp addressed envelope provided. If there is anything at all that is not clear, or if you would like to discuss the project further before deciding, you can email or telephone me.

Once you have signed the consent form agreeing to take part in the project, I will contact you to arrange an interview. This can take place in your home or another

venue if you prefer, and at a time which is convenient to you. The interview will probably last about an hour.

The purpose of the interview is to find out about your experience of being a patient or relative, and to find out why you chose not to make complaint. I am also interested in whether your experience has influenced your own nursing practice.

To allow me to concentrate fully during the interview, our conversation will be audio recorded. This will then be transcribed at a later date.

What are the benefits of taking part?

I cannot say whether being part of the study will be of benefit to you personally, but the information from the study will help Boards to understand that if used sensitively, the information that the ‘insider knowledge’ of nurses who have been patients and relatives are an untapped resource for service improvement. The information will also be used to suggest ways to make it easier for nurse patients and relatives complain when they receive care or treatment which they perceive to be poor, without causing any future detriment to their care, or relationships with colleagues or with their managers.

Are there any risks to taking part?

Being a patient or relative can be stressful, particularly if the experience has been distressing. It is possible that during the interview you may talk about, or be reminded of, an experience which has been difficult for you. If you found the interview to be distressing in any way, I would stop at any point if that was your wish. I would identify with you if there was any support that you might require, either by talking through the issues at the time, or by arranging for you to talk to someone else such as a counsellor.

Will my taking part in the project be kept confidential?

The sensitive nature of this study means that those taking part can be assured that their anonymity will be protected.

The reason the invitation to take part has been given to you by your colleague is so that I will not know your contact details unless you return the consent form. As the

consent form is returned directly to me, no one in NHS xxxxx will know whether or not you have decided to participate. Your details will only be known to me as the researcher.

The recording of the interview will be transcribed by a company who specialise in transcribing interviews for universities and who have strict protocols for maintaining client confidentiality.

The transcribed interviews will be assigned a code so your name will not appear on the paper copies. Your anonymised interview transcript will be shared *only* with my supervisor during analysis of the data. All paper copies and recordings will be stored securely in a locked cabinet which can only be accessed by myself.

There may be rare occasions where the information disclosed in an interview is of such a serious nature, such as the physical abuse of a patient, that the requirement to report to the relevant authorities overrides any confidentiality agreement. In such circumstances the researcher would be required to disclose such information. This would be discussed with the participant and the researcher's supervisor.

What will happen to the results of the study?

The results of the study will be published in academic journals so that the findings can be shared with other health care professionals. Presentations of the findings will also be made locally and nationally to nurses and other health care colleagues, and interested organisations such as the Scottish Health Council, Professional and Regulatory Bodies, the Scottish Public Services Ombudsman and Scottish Government.

Does the study have ethical approval?

Yes. The study has been approved by the University of Stirling School Research Ethics Committee and the NHS Ethics Committee.

What is the relationship between this research and the researcher's day job?

I am an employee of Healthcare Improvement Scotland. My job involves managing the inspection of the care of older people in acute hospitals. My employer has no remit to investigate complaints from individuals. The only information about complaints that I deal with in my day job is at national level. My research is therefore unconnected to my day to day work.

What happens next?

If you would like to take part in this study please complete the consent form and return it to me in the envelope provided along with your contact details. If you do not want to take part, you do not need to do anything further.

What do I do if there is a problem?

If you wish to complain or have any concerns about the way you have been approached regarding this project, you should contact Dr Ashley Shepherd, Deputy Head of School, School of Nursing, Midwifery and Health at University of Stirling.

Thank you once again for taking the time to read the information.

Jacqueline J Macrae Doctor of Nursing Student University of Stirling Tel: 07875 201127 Email Jacqueline.richardson@stir.ac.uk	Supervisor: Prof Brian Williams School of Nursing Midwifery and Health University of Stirling Tel: 01786 466340 Email: brian.williams@stir.ac.uk	Dr Ashley Shepherd Deputy Head of School School of Nursing Midwifery and Health University of Stirling
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APPENDIX 4: Article for submission to Journal of Advanced Nursing
(Maximum 8,000 words excluding abstract, references and tables)

Cause for complaint? The experiences of nurse patients and nurse relatives who receive poor care: A qualitative study

ABSTRACT

Aim: to identify the circumstances in which it would be easier for nurses who find themselves in the role of 'patient' or 'relative' to complain when they have received or witnessed care or treatment they feel could be improved.

Design: A qualitative interview study.

Methods: Data were collected using a semi-structured interview with 12 nurse patients and nurse relatives in Scotland. All interviews were face to face, recorded, transcribed and thematically analysed using Reflexive Thematic Analysis (Braun and Clarke 2013, 2022).

Results: Participants provided rich and often harrowing accounts of their experiences of receiving or witnessing care. The analysis produced the following themes: Insider/outsider (overarching); 1. Through the nursing lens with subthemes (i) It's all magnified, (ii) Blurred boundaries (iii) The hidden code; 2. Loss of trust; 3. See no evil, hear no evil, speak no evil; and 4. Using my insight to make a difference.

Conclusion: While their insider knowledge gave a unique insight into the experience of care and treatment, the complexity of the nurse patient's and nurse relative's insider/outsider position also made it difficult for them to complain when they received or witnessed poor care. Changes to leadership, policy, practice and education are required to make it easier for nurse patients and nurse relatives to complain so that the opportunity to learn from their rich experience is not lost.

Impact: The limited evidence available about the experience of nurses who find themselves in the role of patient or relatives of patients comes from different countries suggesting that this study is of international interest. Previously under researched, this study contributes to the existing body of evidence by looking uniquely at the experience of nurse-patients and nurse-relatives through the lens of complaints.

Key words: Nurse-patient, nurse-relative, nurse-family member, dual role, insider/outsider, healthcare complaints, complaints management.

INTRODUCTION

Complaints can provide important insight into where there is a need for service improvement. If complaints are not received, that opportunity for improvement is lost (Van Dael et al., 2020). However, the NHS has struggled with listening to feedback from patients and effective complaints management since its inception in 1948, with successive high-profile scandals, inquiries (see for example, Robb, 1967; Francis, 2013) and reports (see for example Berwick, 2013; Clwyd & Hart, 2013; Keogh 2013; Scottish Health Council, 2014) leading to changes to policy and legislation in an attempt to improve the culture and encourage feedback and complaints. In Scotland, the Patient Rights (Scotland) Act (2011), the Apologies (Scotland) Act (2016) and Model Complaints Handling Procedure (2017) were introduced to support the shift from a culture of blame and fear, to one of learning and improvement.

There are times when nurses may find themselves in the role of patient or as a relative of someone who is a patient. Nurse-patients and nurse-relatives are not just 'consumers' of the NHS, they work in the NHS and can articulate clinical information. If nurse-patients or nurse-relatives receive poor care and complain they may give a rich account that goes beyond that of the general public supporting learning and improvements in care.

BACKGROUND

Complaint: *'An expression of dissatisfaction by one or more members of the public about the organisation's action or lack of action, or about the standard of service provided by or on behalf of the organisation.'* (Scottish Government & Scottish Public Services Ombudsman, 2017)

Consumer satisfaction/ dissatisfaction with services is complex, taking into account expectations, experience and prior knowledge (Van de Walle, 2018). Originally developed in consumer behaviour research, the dominant theory of satisfaction is the Expectancy-Disconfirmation Model (EDM) (Zhang et al., 2022). The EDM Model suggests that when services exceed expectations (positive disconfirmation) then satisfaction occurs and when services fail to meet expectations (negative disconfirmation) dissatisfaction results. People that have high expectations of a service

are more likely to be dissatisfied than people with low expectations (Van de Walle, 2018).

In his seminal work, Hirschman (1970), argues that there are three main responses when customers or citizens are dissatisfied with goods or services; they will either exit and go elsewhere, they will complain, or when influenced by the level of loyalty they have towards the product or organisation, they may neither exit nor voice but suffer in silence. Exit is a limited option for many who use health services, and the literature identifies two main reasons other than loyalty as to why patients are often reluctant to complain about their healthcare, including concerns that it would not make any difference or might adversely affect future treatment (Clwyd and Hart, 2013; Craigforth, 2009; Scottish Health Council, 2014,). Another important consideration is that when people do complain about the healthcare they have received, it is often at a distressing time and about a subject that can be complex, filled with medical jargon, and difficult to articulate.

When nurses find themselves in the role of patient or relative, their experience is more complex than that experienced by the general public, yet there is a paucity of research in this area. Review of the literature found only 6 studies (7 Papers) (Cohen, McQuaid and Remington, 2021; Elayan and Ahmad, 2017; Duke and Connor 2008; DeMarco, Pickard and Agretelis 2004; Pickard Agretelis and DeMarco, 2004; Salmond, 2011; Zeitz, 1999;) and 2 systematic reviews (Giles & Hall, 2014; Lines et al., 2015) that explored the experience of nurses as patients or relatives of patients receiving care in a healthcare setting.

Having clinical knowledge and knowledge of the healthcare system can have advantages such as greater insight into health conditions, being able to direct care and being included as part of the healthcare team. Being a nurse can result in favourable treatment such as being given more detailed information and the allocation of a single room (Duke and Connor 2008). However, occupying multiple roles can also bring additional anxiety and stress. For example, anticipating the worst-case scenario when waiting for a diagnosis and the feelings of loss of control (DeMarco, Pickard and Agretelis 2004; Duke and Connor 2008; Salmond 2011). Staff can find it intimidating looking after other nurses resulting in nurse patients and nurse relatives experiencing uncaring behaviours such as being avoided or treated less favourably (Duke and Connor 2008).

When nurses are patients or relatives they use their nursing knowledge to assess and make judgements about the standard of care, the competence of staff (Cohen et al., 2021) and about system level issues such as nursing culture, leadership and staffing levels (Elayan & Ahmad, 2017; Duke & Connor, 2008). When care is judged not to meet the standard expected, nurse relatives are known to intervene to prevent harm and to advocate for their loved one (Cohen et al., 2021). While some staff react positively to interventions, others are defensive and feel that nurse family members have overstepped the mark (Cohen et al., 2021; Duke and Connor, 2008). Likewise, when nurse patients or nurse relatives tried to speak to clinical staff about poor standards, their concerns are often not welcomed (Salmond, 2011).

THE STUDY

Aims

The aim of this study was to identify the circumstances in which it would be easier for nurses who find themselves in the role of 'patient' or 'relative' to complain when they have received or witnessed care or treatment they feel could be improved.

Questions:

1. What influences nurse patients' or nurse relatives' decisions about whether to complain about care or treatment they perceive to be poor?
2. What would make it easier for nurse patients or nurse relatives to complain about care or treatment they perceive to be poor?

Design

A qualitative design is suited to questions that require interpretation rather than objective, empirical measurement (Braun and Clarke 2022). Theoretically this study was underpinned by a relativist ontology and a social constructionist approach congruent with the notion that reality is constructed and interpreted from experience and social interaction (Blakie, 2007). The approach to thematic analysis first proposed by Braun and Clarke (2006) and developed over the years into what is now known as Reflexive Thematic Analysis (RTA) (Braun and Clarke, 2022), was congruent with those philosophical and theoretical stances. In a review of 19 articles Newton (et al., 2012) found that reflexivity was poorly reported and often reflected a positivist stance rather than critically acknowledging the researcher's subjectivity and location within the study. RTA, sitting within a qualitative paradigm, enabled the deep, reflexive analysis required to answer the research questions.

The study is reported in accordance with the SRQR check list (O'Brien et al., 2014) and Consolidated Criteria for Reporting Qualitative Studies (COREQ) guidelines (Tong et al., 2007)

Sampling and participants

Participants were recruited in Scotland through advertisement of the study by the Royal College of Nursing and Care Opinion, snowball sampling and word of mouth. The final sample (N=12) was determined by similar previous study sample sizes, review of the data for depth and richness, and reflexive discussions through supervision. The following table introduces the participants:

<Insert table 1>

Of note, 1 participant wanted to tell the stories of her experience as both a patient and as a relative. Two participants described their experiences as being in the hospital in which they were also employed.

Data collection

Data collection was through one semi-structured interview with each participant. Due to the sensitive nature of the subject this was conducted face to face. A participant information sheet was sent to participants with a consent form and the opportunity to ask any questions offered. Informed consent obtained prior to each interview. Participants were advised that they could withdraw from the study at any point. Information was given to participants about where they could get support if they became distressed during or following the interview. Interviews were recorded and anonymised at transcription. Each participant was given a pseudonym.

Interviews were undertaken by the first author and lasted between 45 and 90 minutes. Interviews were arranged at a time and venue that suited the participants. This ranged from some people preferring to be interviewed in their home, others their place of work and a few preferred to come to a quiet space within the first author's office. As an *insider* researcher, that is, a nurse interviewing other nurses, relationships can range from close friends to unknown fellow professionals (Quinney, Dwyer and Chapman 2016). Establishing a relationship built on trust between the interviewer and

interviewee is essential, not just to facilitate an open honest dialogue, but to ensure there is no harm to either party during the interview (Kvale & Brinkmann, 2009). Self-disclosure can help to build a connection with participants (Wood et al., 2019). Each interview by sharing relevant personal experience and explaining the motivation for undertaking the study. A reflexive account was written after each interview.

Ethical Approval

Prior to undertaking the study, ethical approval was sought and obtained from the appropriate university and NHS ethics committees.

Data analysis

Although Braun and Clark (2013; 2022) describe 6 phases of analysis, in practice, it was not a linear progression but a complex process that involved continually going back and forth between codes and portions of data, data items (in this case interviews and transcripts) and the whole data set.

Familiarisation

Familiarisation involved listening to the interview recordings and reading the transcripts many times. Hand-written notes of initial thoughts and ideas were made on hard copies of the transcripts. This included any strong emotions such as anger and sadness so that they would not be lost when working on the analysis from the written text.

Coding

Coding involved naming and labelling sections of text with like meaning. While initially codes were semantic many developed into more latent codes. The following extract shows the initial coding from the transcript from James' (04) interview. A small section has been omitted as although a pseudonym has been used there is a minimal risk that the text could have been identifiable.

< Insert table 3 Coded text extract >

Each code was written on a sticky note and 'like' codes grouped and re-grouped until they were organised into meaningful clusters. Mind maps were then drawn to explore how the clusters linked together.

Generating initial themes

Diagram 1 below shows a summary of the initial candidate themes and the linkages between them. At this point the analysis was beginning to progress but the central organising concepts were not yet fully developed.

< insert Diagram 1 Candidate themes >

The next phase involved continuing to go back and forth between the full data set, the coded data and the reflexive journal while developing further iterations of candidate themes. However, it was not until writing up drafts of the analysis that the level of deep understanding required to interpret some of the meanings that lay beneath the data was realised.

RIGOUR

In RTA subjectivity is acknowledged as an essential driver of interpretation and analysis (Braun and Clark, 2022). For this reason, the situation of the researcher within the study needs to be made explicit. The research was undertaken as part of the first author's Clinical Doctorate (Nursing). It is acknowledged that within this study, the researcher's multiple roles, including the dual role of nurse and researcher; experience as a patient; as the daughter of a mother with Alzheimer's disease who experienced sub-optimal care; and experience in managing patient complaints will have impacted on the every choice made throughout the duration of the study. Reflexivity, became a cornerstone throughout the research process, constantly challenging the researcher's own insider/ outsider role, relationship with participants, the methodological decisions made, and decisions during the many phases of analysis (Findlay and Gough 2003). Keeping a reflexive journal and the use of supervision were the key tools in this process.

To further enhance the quality of the study, two pilot interviews were undertaken to test the semi-structured interview schedule, to enhance interview technique and test the richness of the data generated. As no changes were made following review of the pilot, the data from the two pilot interviews was included in the analysis.

FINDINGS

The following diagram illustrates the thematic structure.

<insert diagram 2 thematic structure>

Insider/Outsider

Insider/outsider is an overarching theme that describes the duality of the nurse (insider) and patient/ relative (outsider) roles. It is through their insider/outsider position that participants provide a window into the experience of being a patient or relative that goes beyond that of a lay person.

Theme 1: Through the nursing Lens

The language participants used was professional and expectations about standards of care were set against their clinical knowledge and experience as nurses. This was illustrated, for example, when Jennifer (P8) said, “the first time I went in I didn’t have a CT scan which is the gold standard for anyone who presents with diverticulitis”.

It was also evident in the extract below from Julie (P7) when she was in the Emergency Department as a patient.

Nobody’s washing their hands, nobody’s putting things in the bin, everything’s just lying all over including dressings, nobody’s putting in Venflons right- all these things that matter. And, then the nurse came in and said, ‘I’m just going to give you this’ and put something in my vein. ‘What’s that?’, ‘Oh, its Morphine’, ‘Oh, right ok’. Didn’t check my name band....and I wasn’t monitored. So, I suppose it’s just my experience of, if you are giving something like that, you don’t know if there is asthma- you need to watch their breathing and all the rest of it but nobody came near.

(Julie: P7)

In setting out their expectations, participants drew on past and present experiences and the wider environmental, cultural and political system of which they were part. Concern about staff shortages and the impact on standards of care featured in the stories of most participants.

The conflict between knowing what level of care should be provided and understanding the context and reality of care delivery in a pressured environment was evident in how participants tried to weigh up the balance as seen in Julie's (P7) further comment, "I was having to stand back and work out if I was being picky or realistic", There were times when some participants second guessed what their expectations should be and whether in fact they had cause for complaint.

a) It's all magnified!

A specific aspect of this theme was not just *what* the participants experienced, but *how* they experienced being a patient or relative. For many, having clinical knowledge increased anxiety as participants anticipated likely outcomes, often fearing the worst.

Recognising poor standards of care led to many participants being hypervigilant, and further increased fear and anxiety. This was articulated by Gillian (P6) in a way that seemed to capture the essence of this subtheme.

Being a nurse is a help and a hindrance. I wish I could just step back and let it go. As a member of the public you have concerns, but this is just ramped up by having the professional knowledge to go 'this is just absolutely wrong'

(Gillian: P6)

For some nurse relatives, while anticipation and fearing the worst was about their loved one's clinical condition, often anxiety was heightened when clinical knowledge was combined with knowledge and understanding of the wider system. As illustrated in the following extract.

The next day there was a change of staff in the High Dependency Unit. The first thing they said was '*oh we'll need to get him [son] out of here and up to the ward*' and that's the first time I sort of thought 'get him out of here today?', even that terminology was like, didn't sit well with me and I said do you think he's well enough?...through the day he had perked up, but me being the nurse, I was watching his temperature fluctuate and at times he was sweating and I thought '*Oh, something's not right*', but I thought maybe it's just me being an over protective mum and having some knowledge. I think it's a dangerous thing in some ways, or maybe you just become a wee bit more anxious about things you think are causing a problem.

(Susan: P12)

Comments such as *'get him out of here today?'* hint at Susan's wider knowledge of the system and the need for patient flow through the hospital. The phrase used had made her question whether her son was being moved because he was clinically well enough, or whether he was being moved because of systems pressures and a need to create capacity in HDU. Although as a nurse she recognised her son's signs and symptoms meant something might be wrong, her role as a nurse was completely intertwined with that of being a mum and her anxiety increased. In common with other participants, she was unsure if she was right or overanalysing the situation, so she did not speak up at that point.

b) Blurred Boundaries

Blurred Boundaries captures the construction of the nurse patient/ nurse relative role on the insider/outsider continuum with 'being a nurse' at one end and 'being a patient/relative' at the other. It relates both to the ways in which the participants constructed their own internal meaning and identity, and how they wanted to be seen by other healthcare professionals. Where the participants were on the continuum was fluid. It moved constantly depending on their situation and often linked to feelings of vulnerability and loss of, or taking, control.

The impact of role boundaries featured in different ways. For some participants there was a dilemma about their responsibility as a registrant to report unsafe practice they felt breached The Code (NMC 2018) to the Nursing and Midwifery Council. On more than one occasion during her interview Joan (P3), said that she felt responsible for what she was seeing, an example of which is evident in the extract below:

"The ward was unsafe. I was concerned not just for my dad but for the other patients and I felt responsible for what I was seeing... So, there was a real dilemma for me as a registrant too because the place wasn't safe for anybody, so there was the issue of my dad's care, but also as a registered nurse I was witnessing a really unsafe situation." (Joan: P3)

While participants were happy to help their relatives and as patients do as much as they could to be self-caring, lack of visibility of staff and the expectation that they would deliver care and increased the burden and stress. While nurse relatives were sympathetic towards staff shortages, they also resented the fact that there was an assumption that they would just take over.

“His management really involved a complete abdication of care to myself and my mother. I’m a mental health nurse but it’s different when it’s your father – to be sitting with someone who was completely not the person that you know, who is delusional, agitated, probably potentially aggressive’,

(Joan: P3)

Being put into the nursing role by family members also challenged participants personally and professionally.

My sister-in-law used to say to me ‘*please talk to [brother] as a nurse, because he won’t talk about cancer to anyone. I’d like you to talk to him*’. I tried a couple of times to get him to talk because that’s what everybody wanted, and I had a sense of failure as a nurse and as a mental health nurse, because you know, I’m supposed to be able to get people to talk and I couldn’t even do it for my brother.

(Pat: P9)

Role ambiguity between the nurse patient/relative and professional role was further complicated by the extent to which participants felt a duty of care and responsibility for other patients. For example, Jennifer (P8) observed the nurses leaving a lunch tray in front of a lady who was blind, rather than call a nurse she stepped into her nurse role and assisted the lady herself.

c) The Hidden Code

The Hidden Code is the construction of a world of avoidance, concealment and fear that links strongly to the participants’ experience being ‘all magnified.’

Many participants spoke of a general lack of compassion from healthcare professionals. However, *The Hidden Code* refers to the way participants felt they were treated as a **direct** result of their nursing role. In some cases, participants felt as if they were actively avoided because they were nurses, and in others, they actively tried to conceal the fact that they were nurses. The reason for this avoidance / concealment on the grounds of role was not always explicit.

I try not to say I’m a nurse, but then I might ask something that gives the game away and I try not to do it. I try not to use professional terms or anything. I asked some questions that were pertinent about her bloods and they said ‘Oh

are you a nurse?' and I said 'yes I am'. 'Oh right, ok' you could practically see them recoil, especially nurses that were considerably younger than me.

(Gillian: P6)

Nurses observe each other's practice all the time at work, so it is interesting that this dynamic changes when the nurse is a patient or relative. *The Hidden Code* implies that if you are a nurse in the role of a patient or relative you are treated differently. The Code that upholds the standards of the profession and that states that people must be treated with '*kindness, respect and compassion*' (NMC 2018) appeared not to apply when the patients or relatives were also members of the profession. Rather, they were something to be feared, avoided and not engaged with.

The impact of nurses acting as if they are fearful and avoiding patients and relatives is significant, not only by adding to an already stressful situation for the participants, but the lack of visibility and approachability was impacting on good communication and the ability to listen to and sort any concerns as they happened.

Theme 2: Loss of trust

This theme developed initially from the analysis of the code *loss of trust*, a semantic code that was expressed explicitly by some participants Gemma (P1):

I said '*I trusted you implicitly, why didn't you [admit mum to hospital]?*' And I think he could see the disappointment, the lack of trust thereafter. I moved GP practice and mum did as well. I just couldn't trust him again.

(Gemma: P1)

However, although not all participants explicitly used the word trust, the loss of trust was implicit within the narrative of most.

From an insider perspective, there was an expectation that their colleagues (both those they worked directly with and colleagues in the wider sense) would uphold the highest standards and when their expectations were not met, there was anger and disappointment amongst most participants. They described not just losing trust in the service they received, but with the wider health service and the nursing profession.

For a few like Pat (P9), the experience was still having a significant impact on their wellbeing:

I was just furious, I mean furious and I know I've got a real kind of, you can probably hear it now, a real emotional – ahhh! Just like a badness, like a, like a puss that's sitting there, that is still full of anger you know.

(Pat: P9)

What was apparent with many of the participants was that the loss of trust was deeper than that of a patient-clinician provider. The impact of loss of trust and the feelings of anger, disappointment and shame at being let down by the profession were deep and enduring.

Theme 3: See no evil, hear no evil, speak no evil

One of the interesting findings that felt apparent during the interviews, and was confirmed through the analysis, was that while participants were very keen to talk about their experience, even although this was at times harrowing and they often became visibly upset, they appeared less confident and more reluctant when it came to discussing whether or not they should have complained.

See no evil

When a third party such as a relative, friend, Councillor, MP/MSP complains on behalf of a patient, the patient's consent is required to enable a response to be sent. One of the issues the nurse relatives struggled with was the need to have the patient's consent to allow them to complain. This was particularly difficult when they had witnessed the poor treatment when visiting their loved one, or where they themselves felt like they had been treated badly by staff. At times of bereavement, nurse relatives in the role of protector felt they could not ask their loved one for consent.

Then it was like *we'll have to get your wife's date of birth and more information*'. I felt like I was kind of dragging her into something knowing that she wouldn't have wanted to complain, so I put feedback and that was the last I heard.

(James: P4)

This was extremely difficult for participants on many levels. Not only were the nurse relatives coping with their own grief, they were supporting their family members. For each of these nurse relatives there was a feeling of sadness and frustration that they could not act on what they themselves had seen or witnessed.

Hear no Evil

For some participants this was strongly linked to *The Hidden Code* where resistance to hearing negative feedback was related to their nursing role. An example of this can be seen in the extract below from Julie (P7):

Before I left, I did ask to speak to the ward manager....but when she came in she said, '*Everybody is up in arms because they think you are going to do nothing but complain about them*' and I said '*no I'm not*'. I thought I would give her some positive feedback as well as negative.

(Julie: P7)

For some participants, the lack of an acknowledgement and apology added to their anger and distress as evident in the extract from John (P2).

Often an apology is all people want to hear, '*I'm sorry this has happened, it shouldn't have. I'm really sorry and this is what we are going to do*'. But there was none of that.

(John: P2)

Speak no evil

When exit is not possible, some people who receive a poor service will suffer in silence rather than voice, particularly if voice is perceived to have negative consequences. Some chose not to complain because they did not want to get staff into trouble, they did not think the issue was serious enough, or they did not want to add to the burden of overworked staff. For others, they would not just be complaining about 'staff' but colleagues they worked with and they were concerned about repercussions.

I wouldn't [complain] because of where I am in the organisation. My surname's unusual so people would immediately know it was me...[pause].... I mean I'm not looking to further my career, goodness no, I don't want to go further than this, but ...[pause]...I don't know

(Julie: P7)

Theme 4: Using my insight to make a difference

The theme *Using my insight to make a difference* refers to two constructs. The first relates directly to the research question and what, from their experience, participants thought could be done to make it easier for nurses who found themselves in a similar position to give feedback or complain. The second refers to the lasting impact the

experience had on the participants professionally and how some made changes to their own practice as a result of their experience.

Making it easier to complain or give feedback

One of the surprising findings was that even when asked directly '*What, if anything, would have made it easier for you to give feedback or complain?*' most participants like April (P11) struggled to answer. 'I'm not sure what, if anything, would make it easier' (April: P11), and a few were unable to comment at all.

For some, their hesitancy may have related to their uncertainty about the complaints procedure and the definitions within the Patient Rights Act (2011) as illustrated when Shirley (P5) commented, 'How do you make the distinction between a formal complaint and informal feedback?'

A few participants did make suggestions about how to make it easier to give feedback. Some had seen feedback forms in wards that they had previously worked in and suggested they should be made more widely available for all patients.

Some participants suggested removing the negative connotations of the word complaint 'Not calling the complaints department complaints would help so feedback is not automatically considered a complaint'.

(Jennifer: P5)

Making a difference through my own practice

Although most participants had not given feedback or complained, they remained concerned that the consequence of them not doing so meant that the opportunity for others to learn from their experience was lost. A few described how they had used their experience to make changes to their own practice or had considered how they might share their experience to help others learn. Joan (P3) and Pat (P9) were both nurse educators but had very different stories about how their experiences had influenced their work.

'We will definitely be including more about shared care versus dumped care, and yes, we can use the scenario about a family, what support a family needs in a situation like I've described without saying *'this happened to me'*.

(Joan: P3)

In the extract below, Pat (P9) describes the impact various experiences of poor care, both as a patient and as a relative, had on her professional life. During a lecture she had referred to her experience of being a relative to illustrate a point.

It did [impact] for a while. All of the stories did for a while and I think I was a bit of a loose cannon. I think it does affect...[pause]..something like having the experience of my sister, very close to me, and I can't actually remember what I said, but some sort of aside connection to the story and I thought I could get away with it and certainly with students, they know immediately, they know when it's something close to you and it produces absolute silence in the lecture theatre. It's very effective, but its emotionally too hard and yes, I couldn't. I've learnt not to tap into it. I'm just too vulnerable I think.

(Pat: P9)

Both Joan (P3) and Pat (P9) recognised the power that their stories could bring to the learning environment but were also aware of the need to keep professional boundaries with students. For Pat (09) the experience remained too painful.

Discussion

There is a paucity of research that considers how nurse patients and nurse family members experienced care and to my knowledge, this is the first study that set out to discover whether nurse patients and nurse relatives who were dissatisfied with the care they received, or witnessed, complain. The research asked 2 questions

Question 1: What influences nurse patients' or nurse relatives' decisions about whether to complain about care or treatment they perceive to be poor?

Expectations versus Experience

In line with the literature, the nurse-patients and nurse-relatives in this study experienced care differently from lay people. Salmond's (2011) study also revealed that the patient-nurse and relative-nurse roles were completely intertwined. Participants moved (often within one sentence) back and forth along a continuum between their patient/relative and nurse role, and their expectations and experience shifted depending on which point of the continuum they were at any given time.

Comparable to the findings from the literature, the data found that the multiple personas participants occupied led to additional stressors such as emotional turmoil, increased fear and anxiety, and feelings of powerlessness and loss of control (Lines et al. 2015). In addition, the data from this study found that the stressors were, as Gillian (P6) described, '*ramped up*' further when participants experienced or observed care that at best did not meet their expectations and at worst was unsafe. Witnessing poor practice or unsafe care led to an inability to 'switch off'. While Salmond (2011) found that family members hyper-vigilance over their loved one helped them maintain a sense of control, for the nurse relatives and nurse patients in this study, hypervigilance was often due to the anxiety caused by receiving or witnessing substandard care.

Like the findings from the literature, analysis of the data from this study found that participants judged the quality of care they received or witnessed through their nursing lens. (Cohen et al 2017; DeMarco et al 2004, Duke and Connor 2008; Elayan and Ahmed 2017; Picard et al 2004; Salmond 2011; Zeitz 1991). In doing so, participants drew on their clinical knowledge, their knowledge of professional standards, and their current or previous clinical experience.

The EDM suggests that people with higher expectations are more likely to experience dissatisfaction (Van de Wall 2018; Zhang et al 2021). Some participants talked about expecting the *gold standard* and used clinical standards as their reference point. However, when the gold standard was not achieved, as insiders, participants spoke about their experience in the context in which that care was being delivered. Drawing on their professional experience, many commented on staff shortages and the delegation of care to healthcare support workers. For some participants this caused significant tension. On one hand they expected care to be compliant with the professional standards they knew, but on the other, they questioned whether they were being 'too idealistic' or 'picky'. For others, the expectations were less about the technical aspects of care but about being treated with compassion and care. Here participants often drew on The Code (NMC, 2018) to articulate the values and behaviours they expected to see.

Blurred boundaries and role ambiguity led to confused expectations of the amount of involvement that nurse relatives were expected to have in their loved ones' care. From the literature, '*being let in*' and included as part of the care team was an important factor in reducing anxiety and fear (Salmond, 2011 and DeMarco *et al.*, 2004). The

data in this study showed that while participants expected to be involved in communication about care and treatment, some felt that staff expected too much from them and that they were left to carry out often inappropriate levels of personal care.

Divided loyalties

Relationships with family members and staff influenced whether nurse relatives would complain. Nurse-relatives were conflicted by their desire to complain and need to have their relatives' consent. Not being allowed to give feedback had a lasting impact on participants with some still feeling regret at the time of interview.

For most participants, being on the receiving end or witnessing the poor care of their loved one, led to deep feelings of disappointment, shame and loss of trust. However, for many participants, despite feeling let down, particularly by the nursing profession, there was still an underlying feeling of loyalty. While they did not want to get staff into trouble (Craigforth, 2009; Scottish Health Council, 2014), for the participants in this study, it went beyond the idea of reporting 'staff' to reporting 'colleagues'. Participants did not want to be seen as the stereotypical complaining nurse (Duke and Connor 2008) for fear of causing less favourable treatment (Craigforth, 2009; Scottish Health Council, 2014).

Many participants in this study pondered for weeks over whether to complain about their experience and at the time of interview some were still torn while others regretted not complaining. Again, the insider outsider conflict was apparent for many, between complaining as outsiders and complaining about a service, standards and culture that they were part of as insiders.

Culture of fear and reluctance to listen

The landscape of successive reports and inquiries described a culture of fear surrounding feedback and complaints and a reluctance of the NHS to welcome feedback and to listen (Berwick 2013, Craigforth 2006; SHC 2014). The data found that this was still evident in the narratives of participants in this study.

Unlike the general public, the fear was deeply rooted in their nursing role. For the majority, this was apparent even when they, or their loved one, were being cared for out with their place of work and they had no personal relationship with staff. While Duke and Connor (2008) and Salmond (2011) found evidence that nurse patients and nurse

relatives had a better experience of care when they were admitted to their place of work, this was not the case for Julie (P7) and Susan (P12) who had the increased concern about confidentiality and the impact complaining would have on their jobs.

Most participants were fearful of staff's reaction to finding out they were nurses and took active steps to conceal the fact. When they were found out, some modified their behaviour to make it less intimidating for staff looking after them (Salmond 2012). For others, in line with Connor and Dukes' (2008) findings, there were times when staffs' fear of looking after nurse patients, or communicating with nurse relatives, meant that participants were avoided. This avoidance not only added to their anxiety and poor experience but prevented staff from having the opportunity to resolve concerns early in line with the Model Complaints Handling Procedure (SPSO).

While participants in the studies by DeMarco et al (2004) and Salmond (2011) reported that they recognised staff could feel intimidated looking after other nurses, what was not evident in the literature was the reason *why* this should be the case.

Nurses observe each other's practice all the time, so a significant issue for consideration is why is it so different when the nurse is a patient or relative.

Some participants did speak directly to clinical staff about their concerns. Evidence from the literature and from national reports found that feedback to NHS staff about standards of care was not always welcome (Cohen et al 2021; Salmond 2011; Scottish Health Council, 2014) likewise, the response was mixed findings with some staff responding positively, while others were immediately defensive.

Question 2: What would make it easier for nurse patients or nurse relatives to complain about care or treatment they perceive to be poor?

Unlike Elayan et al (2017) who found that nurse patients were uncomfortable verbalizing unpleasant experiences, the nurse patients and nurse relatives in this study were very anxious to tell their story when interviewed. However, they were less confident in discussing what would have made it easier for them to complain. What became evident during the analysis was that making it easier to complain went beyond simply improving individuals' knowledge and understanding of the complaint's procedure.

Person Centred Practice

The findings in this study are consistent with the literature reporting that the experience of nurse-patients and nurse-relatives is different from that of lay people, with role conflict, heightened anxiety and competing expectations being common. For this reason, nurse-patients and nurse relatives require a person-centred approach that does not make assumptions about the level of involvement expected or the level of clinical knowledge, but asks individuals how involved they want to be and what level of information they need (DeMarco et al 2004; Duke and Connor 2008; Salmond 2011). It also means staff having the confidence to find out what is worrying nurse relatives and nurse patients and rather than avoidance, to acknowledge their dual role and be present in providing support (Duke and Connor 2008).

There needs to be greater understanding that the very people that could provide rich insight into the quality of services have additional barriers to complaining, such as struggling with role identity, professional shame and fear.

Removing the fear and listening

Since the failings in Mid Staffordshire NHS Foundation Trust, there is a greater understanding that a culture of fear presents a significant risk to patient safety and quality improvement there have been calls to drive out the culture of fear from the NHS (Berwick 2013; Clwyd and Hart 2013; SHC 2014). However, the findings from this study suggest that for nurse patients and nurse relatives, there is still some way to go. There was an additional layer of fear for many of the participants in this study as a result of their insider knowledge of their care and treatment that was exacerbated when that care or treatment was found to be poor. Similar to the findings in the literature (Duke and Connor 2008, Zeitz 1999), what also came through strongly was the how intimidating and daunting it was for staff looking after other nurses and the resultant avoidance behaviour experienced at a time when the participants were at their most vulnerable and needed most support.

The Code (NMC, 2018) was referred to by several participants throughout the interviews and analysis of the data suggests that the principles and values of The Code are not always upheld when the nursing profession looks after its own. With a greater understanding of the fear and vulnerabilities many nurse patients and nurse relatives experience and understanding that the stereotypes of the nurse patients and nurse relatives as 'complaining' are largely unfounded (Duke and Connor 2008), staff may

be less fearful in approaching and engaging with nurses both in the delivery of person centred care and in actively soliciting feedback.

The complaints process

All participants in this study expressed a level of dissatisfaction with the care they had received or witnessed that would have fitted with the definition of a complaint. However, despite the introduction of the Patient Rights Scotland Act (2011) and recent focus by the Scottish Government, SPSO and NHS boards on improving complaints management, few participants knew or understood the definitions of feedback, comments, concerns and complaints. The majority spoke of giving 'informal feedback' or making a 'formal complaint' which they believed had to be in writing.

Identified as a recommendation in *Listening and Learning* (SHC 2014), the Model Complaints Handling Procedure (2017) places a duty on NHS Boards to resolve complaints early and for frontline staff to have ownership. However, the avoidance and lack of engagement of staff with participants in this study meant that opportunities to listen and put things right at an early stage were often lost. Participants who spoke directly with clinical staff were met with a mixed response. Despite apology being identified by the SPSO (2021) as *more likely to resolve a complaint than any other action*, the lack of apology and acknowledgement added to their anger and distress. Participants were not looking for someone to blame; they understood the context that staff were working in, but what they did want was for staff to be accountable and acknowledge where there had been failings in care.

It is inevitable that the quality of health services will sometimes fall below that expected and that mistakes will occur. Good complaint handling can restore trust and put things right. Welcoming feedback from nurse-patients and nurse-relatives, is not only important in terms of remedying the poor practice experienced but to restore trust and confidence. Failure to do can have a devastating and enduring impact on their wellbeing.

Limitations

This small-scale study was undertaken as part of a part-time clinical doctorate programme. As such, there were expected limitations in terms of resource and time available that were accounted for in the study design.

While the data collected was rich and contained a range of views, a larger sample may have improved the findings by widening the range of differing views. Within the sample, 5 out of the 12 participants were working in education or clinical research. This may have been because the study was mainly advertised through the RCN bulletin. Wider advertisement may have led to a more diverse sample.

None of the participants in the study had their dissatisfaction resolved under the complaint's procedure. It may have added additional depth and perspective to explore the outcomes for those who had been through the complaints process and what factors had enabled them to do so.

Despite the limitations, this study provides a valuable contribution to the existing small body of knowledge about the experience of nurses who find themselves in the role of patient or relative. It has also gone some way to addressing a gap in the literature by presenting new knowledge relating to the circumstances in which it would be easier for nurse patient and nurse relatives to give feedback or complain when they experience care they perceive to be poor.

CONCLUSIONS

This study builds on the existing, limited body of knowledge from the international literature about the unique way nurse patients and nurse relatives experience care. The findings also contribute new knowledge by addressing an identified gap in the literature about how the multifactorial way care was observed, judged and experienced by nurse patients and nurse relatives influenced their decision to complain when they received or witnessed care that did not meet their expectations.

If services are to tap into the knowledge and experience of nurse-patients and nurse-relatives for learning and to improve the quality of care, it is essential they are empowered to complain without fear of a detriment to their care or working life.

Recommendations

Leadership and policy

Policy development should continue to focus on welcoming complaints and other forms of feedback within the context of a learning and improvement culture. In enacting

policy, senior leaders should continue to work towards a quality and safety culture that drives out fear.

Senior leaders should support practitioners to be confident in looking after other healthcare professionals and to pro-actively engage with rather than avoid them, and staff should be actively supported to encourage nurse patients and nurse relatives to question care and give feedback without fear of consequences to future care when that feedback is highlighting poor practice or patient safety issues.

Practice

The care of nurse patients and nurse relatives needs to be truly person centred. Practitioners need to understand the unique way that care is experienced and the potential additional stressors that occur as a result of having clinical knowledge and balancing multiple roles. Staff should enquire as to what level of knowledge they want and need, as well as how involved nurse relatives, with consent of the patient, expect to be involved in decisions about and delivery of their loved one's care.

Education

The evidence from the literature and from this study suggests that health professionals, particularly nurses are ill prepared to look after other nurses. As part of the education on person centred practice, consideration should be given as part of the curriculum for undergraduate nurses to prepare them for looking after healthcare professionals. The use of nurse patient /nurse relative stories would give students insight into the unique way that nurses experience care when they are patients or relatives while giving the opportunity for nurse patients and nurse relatives to be heard and contribute to making a difference.

NHS Board Patient Experience Teams are expert in complaints policy and procedure and support staff to manage feedback and complaints. Consideration should also be given to educating Patient Experience Teams about the unique way nurse patients and nurse relatives experience care and the additional barriers they face to complaining. This would enable them to better support nurse patients and nurse relatives to give feedback or complain and support staff who are being complained against.

Further research

A study to explore the experience of nurses looking after other nurses would complement this study by providing greater insight into why it is so difficult and why nurses avoid nurse patients and nurse relatives.

While this study examined the experience of nurse patients and nurse relatives through the lens of poor experience and complaints management, it is important to stress that nurse patients and nurse relatives will experience excellent care. It is equally important that learning is shared when things go well as when mistakes are made. Research into the positive experiences of nurse patients and nurse relatives would also compliment this study.

Conflicts of interest

The authors declare that they have no conflict of interest.

Author Contributions

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Tables and Diagrams for JAN article

Table 1

Introducing the participants

No.	Pseudonym	Length of time qualified	Specialty (for most of career)	Patient/relative	Setting of experience	In own place of work?
01	Gemma	>10 years	Dermatology	Relative – patient was her mother	Primary care	No
02	John	>10 years	Medicine of Elderly	Relative – patient was his mother-in law	Hospital - care of elderly	No
03	Joan	>20 years	Education	Relative – patient was her father	Hospital Acute	No
04	James	>5 years	Education	Relative – patient was his wife	Hospital clinic	No
05	Shirley	>20 years	Research Clinical Nurse	Patient	Hospital clinic & primary care	No
06	Gillian	>20 years	Research	Relative – partner was the patient	Hospital Acute	No
07	Julie	>20 years	Hospital Clinical Management	Patient	Hospital Acute	Yes
08	Jennifer	>20 years	District Nurse	Patient	Hospital Acute	No
09	Pat	>20	Education	Both patient AND relative to her sister, brother and mother-in-law	All experiences in Hospital Acute	No
10	Samantha	<5	Surgical Nurse	Relative – patient was her mum	Hospital surgery	No
11	April	>20	Orthopaedic Nurse	Relative – Patient was her Mother-in-Law	Hospital Medicine of Elderly	No
12	Susan	>20	Hospital Clinical Management	Relative- Patient was her son	Hospital Acute	Yes

Table 2
Extract from initial coding

Extract	Code
<p>Unfortunately, after seven weeks, the pregnancy didn't continue and she was told she'd have to have a medical miscarriage [text omitted], so we were asked to come into hospital to go through that process. Leading up to that point everything, you know I thought the service was excellent and we were kind of handled with dignity and respect you know through a pretty difficult time. But it was the experience at the hospital which left me with a pretty horrible taste in my mouth; you know we'd been asked to turn up to a ward at a certain time and as you can understand we were both pretty gutted you know and in a pretty horrible state anyway and when we got to the ward we were just told sit in the corridor for, you know the nurse is on her break or something or whatever having a coffee. So we sat there for about forty five minutes and had to go and ask again you know, if someone's going to see us and we were eventually taken to a room and kind of left there for another hour without anyone coming in at which point you know, we didn't know what was going to be happening, what to expect and obviously we were both in a pretty bad emotional state. We were seen by a doctor who was going to explain the procedure but you know his first words to us were you're here for a termination which I said you know well that makes it sounds like this is something that we've, you know the pregnancy was something we didn't want which is you know very far from the truth but you know he didn't really respond to that and he went onto explain what would happen and we'd be given medication.</p> <p>There were some nice nurses that took some time with us and talked to us and you know expressed some sympathy but on the whole I found the nurses to be quite cold and dismissive of us which wasn't really what I would want in that situation or my wife would want. So I mean we left it, we got discharged at like one in the morning and we were both pretty distraught after the experience; it was sweetened somewhat by the medic that did the last procedure, you know took loads of time with us you know kind of reassuring my wife that you know this was nothing, because she was quite concerned that she'd done something to bring on the miscarriage or you know somehow it was her fault but the medic took you know a really long time with her and was really nice and that's what I would have expected from a healthcare professional. So it wasn't for a while after, I think I stewed about it for a couple of weeks, I know my wife didn't want to complain although she was pretty upset by the treatment so I write an email to the complaints department.</p>	<p>NC (description of experience)</p> <p>Positive Experience</p> <p>Feelings about the poor experience</p> <p>Impact of the experience</p> <p>Being avoided Staff backing off Being Vulnerable</p> <p>Level of information</p> <p>How complaints and feedback are received</p> <p>How complaints and feedback are received</p> <p>Positive Experience</p> <p>Staff attitude</p> <p>Emotional impact</p> <p>Positive Experience Deciding to complain/ indecisive Needing consent Making a complaint</p>

Diagram 1

Candidate Themes

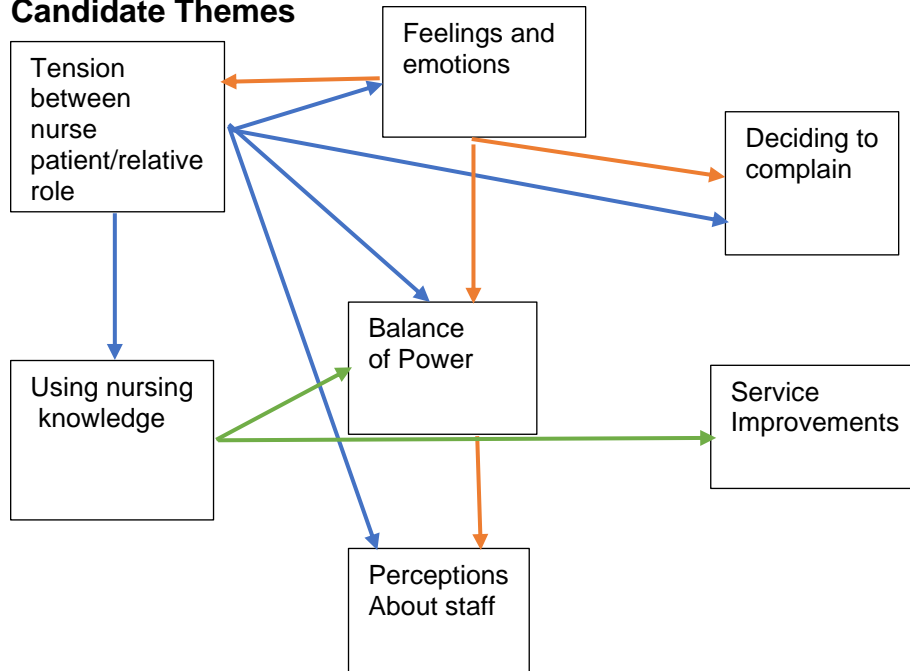


Diagram 2

Thematic Structure

