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The lived experience of dietitians'
involvement in decision-making related to
artificial nutrition and hydration.

by

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of Philosophy in Health and Social Studies

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Declaration of Authorship

This thesis is my own work and has not been submitted for a degree at another university.

Aspects of this work has been presented at conferences as abstracts, posters and oral presentations (as outlined below). The abstracts and posters were first authored by myself, however my supervisors commented on the submissions and were cited as additional authors.

Tighe BJ, Blackburn C, Slowther A (2014a) Emotion Work Associated with Personal Faith. European Conference on Religion, Spirituality and Health, Malta

Tighe BJ, Blackburn C, Slowther A (2014b) 'Being Heard' Dietitians Involvement in Making Decisions about Artificial Nutrition and Hydration. *European Journal of Food Research & Review*, 4(3), 216-7.

Tighe BJ, Blackburn C, Slowther A (2013) It starts to look like force feeding to me. British Association of Parenteral and Enteral Nutrition conference, Harrogate.

Abstract

Background

Artificial nutrition and hydration (ANH) is the provision of nutrition and/or fluid via artificial means into the gut or into the blood. Decisions about ANH can be difficult and emotive. Dietitians assess patients to recommend whether ANH is indicated, and manage patients once ANH has begun. This research aimed to give voice to dietitians' experiences of their involvement in decision-making about ANH, by exploring dietitians' perceptions of their role and exploring how different contexts influenced dietitians' experiences of decision-making about ANH.

Methods

Sixteen dietitians were interviewed twice for a qualitative phenomenological study which explored their experiences of decision-making related to ANH. The transcribed interviews were analysed using an interpretive phenomenological framework.

Findings

Three themes emerged from the data: 'so much more than just deciding on a feed'; 'wanting to be heard'; and 'the emotional roller coaster'. Professional autonomy, being recognised as an expert, and wanting to be involved in decisions were important for all participants. Some participants were involved in decision-making and some implemented decisions made by others. When their professional expertise was not recognised, the emotional experiences were negative. Emotional labour and moral distress were displayed by some. Professionalism was shown by speaking out and acting as moral agents. Some believed that their emotions should not be shown. None of these experiences have been reported by UK dietitians before.

Conclusions

This study contributes rich and complex new knowledge to the understanding of dietitians' experiences. These experiences included strong and complex emotional responses and correspondingly complex strategies to cope, which enabled dietitians to protect themselves, colleagues, and patients. Professional identity and challenges to their professionalism were also important aspects of their experiences. This research has expanded the concept of professionalism within dietetics. Implications for practice include the need to develop emotional intelligence and for dietitians to raise their profile by building strong collaborative partnerships with healthcare staff to facilitate their professionalism. Guidance on ethical decision-making for dietitians is required.

Chapter 1: Introduction

1.1 Background

Illness and chronic diseases are often associated with a decrease in appetite and, normally, a corresponding decrease in food intake. Surveys from the British Association for Parenteral and Enteral Nutrition (BAPEN), report that between 29% and 34% of adult patients who were screened on admission to hospital were found to be at risk of malnutrition (Russell and Elia, 2014). In care home populations this increased to 41% of those screened on admission (Russell and Elia, 2012). As the UK population ages and medical interventions become more complex, the need for nutrition support to meet patients' nutritional requirements is likely to increase. Patients with malnutrition or those at risk of malnutrition may require nutrition support in the form of extra oral food or drink, or through artificial nutrition and hydration (ANH), that is, the feeding or giving of fluids via a tube into the gut or into a vein.

The adequate provision of food and drink, orally or via a tube, has the potential to generate strong emotions in those involved in caring for patients, their relatives, and the general public. Food and drink have great symbolic importance (Blandford, 2011): Caspar (1988) noted the caring symbolism of food, while others have described food as having a nurturing role (Modi *et al.*, 2010; O'Sullivan Maillet *et al.*, 2013). Not providing adequate nutrition via ANH is often viewed as starvation (Whitworth *et al.*, 2004; Kitzinger and Kitzinger, 2014a). However, a reduction in oral intake

is common in people who are dying (National Clinical Guideline Centre, 2015).

The effects of malnutrition can be perturbing. Poole and Froggatt's (2002) review of the literature notes that weight loss and/or a loss of appetite associated with illness can be more troubling for relatives and healthcare professionals caring for patients than for the patient themselves. Ball *et al.* (2014) described the emotional challenges for carers of patients with dementia who have feeding problems, such as anxiety when food intake is poor and battles to try to promote eating. Bryon *et al.* (2010) suggested that families see the provision of ANH as a way to show comfort and care. Indeed, in a systematic review of nutrition support at end-of-life conducted by del Río *et al.* (2012), there was evidence that some families were so troubled by their relative's lack of oral intake that they insisted on their relative being force fed.

Decisions about ANH can be complex, difficult, and troubling, and have an added level of complexity when people are unable to make decisions for themselves. Dietitians should have a key role in decisions about the provision of ANH (Andrews, 2004; Chakladar, 2012). They are likely to be involved in the discussions about ANH and will implement the decisions made. However, little is known about what dietitians think about this and the impact for dietitians when working in this potentially emotive area. Therefore, the aim of this research was to address the question, 'What are dietitians' experiences of being involved in decisions relating to ANH?'

In this introductory chapter, I will explore my interest in the area of research, why dietitians are an important professional group with which to undertake research, and give a brief outline of the thesis structure.

1.2 My interest in the area of research

As a registered dietitian, I have always been interested in decisions not to provide ANH to patients. I recall as a graduate dietitian in my first job being troubled when patients received intravenous fluids, but did not receive nutrition. I could not understand why patients were being hydrated but not fed. Were these patients being left to starve as their relatives suggested? This interest grew during my master's degree which included a module on ethics. It led me to consider dietitians' ethical practice related to ANH, and questions such as how much do dietitians consider ethics when ANH is withheld or withdrawn? How often are patients coerced into accepting feeding tubes? Should restraints be used to stop patients removing feeding tubes? Could using restraints to stop feeding tube removal be viewed as force-feeding? Is consent for tube feeding always obtained and if not, why not? These issues are complex and challenging, and are important for patient care and the professional practice of dietitians.

1.3 Why explore dietitians' experiences?

Dietetics is a growing profession. In 2015 there were 8,598 dietitians registered with the Health and Care Professions Council (Health and Care

Professions Council, 2015a) of which about 95% were female. Dietitians work in a range of settings, including hospitals, GP surgeries, and community settings, and are an important part of the NHS workforce and multi-disciplinary teams. Dietitians have a role in the prevention and treatment of malnutrition by assessing and monitoring patients who receive ANH (Armer and White, 2014). Dietitians are experts in nutrition and as such should be involved in decision-making about nutrition as part of the multi-disciplinary team (Andrews, 2004; Chakladar, 2012). Dietitians have a role in providing information which patients may use to inform their decision-making process (Peregrin, 2002; The British Dietetic Association, 2008a), such as information about treatments and their effects. Dietitians should speak up for their patients and act as patient advocates (The British Dietetic Association, 2008a; The Scottish Government, 2012; The British Dietetic Association, 2013; Health and Care Professions Council, 2016). They may also have a role in helping patients and carers to consider the best treatment plan for them as individuals, which may differ from the dietitians' goal of meeting full nutritional requirements. The involvement of dietitians within the decision-making process has the potential to benefit patients, aid team working, enhance team communication, and help dietitians to understand the decisions made. While dietitians are likely to be involved in the decision-making process, the ultimate decision rests with the patient (if they have capacity) and the doctor in charge of the patient's care.

While dietitians are likely to have a key role in decision-making about ANH, American dietitians have been criticised for not using their expertise and taking a 'back seat' in decision-making (Peregrin, 2002:841). Dietitians not using their expertise and not being proactive during decisions about ANH has the potential to affect patient care and may affect the professional standing of dietitians within the multi-disciplinary team. Until now, there has been no research to explore if Peregrin's (2002) article is valid for UK dietetics, as there has been a lack of research exploring the experience of dietitians' involvement in decision-making about ANH. This is an important gap in the knowledge base of dietitians' professional practice. Therefore, this research has the potential to contribute to this scant evidence base and may inform professional practice and highlight training needs.

Chapter 2 outlines that decision-making related to ANH can be complex, troubling, and emotive; however, it is not known if dietitians have this view. Exploring whether dietitians experience these situations as complex, troubling, and emotive is potentially important to dietitians both professionally and personally. For example, it may indicate that dietitians working within ANH need more support. Support is key to professional practice and was a recommendation made by Francis (2013) in his report into poor care at Mid Staffordshire. There is no research about dietitians' experiences of working in ANH, therefore there is a gap in the knowledge base about if UK dietitians need or are getting adequate support. Therefore, this is an important area to explore.

While there is no evidence about dietitians' experience of involvement in decision-making about ANH, there is research with other professional groups which can be drawn upon to inform this research. Chapter 3 will review the literature with other health professionals, such as nurses, which will highlight some of the difficulties that they can have when they are involved in decisions about ANH. This includes some emotive elements that nurses and other health professionals describe during decision-making about ANH. Therefore, as little is known about UK dietitians working in the area of ANH, exploring dietitians' experiences of being involved in decisions about ANH could illuminate important aspects of their professional practice, which may be of importance for individual dietitians as well as for the wider profession.

UK dietetics is a growing profession with scant literature regarding their professional practice. This research will contribute new knowledge by illuminating dietetic practice within adult nutrition support. The results will be of importance to dietitians, dietetic professional associations, clinical educators, and university lecturers. It may inform new practice guidelines to complement existing codes of conduct. It may also be of interest to other members of the multi-disciplinary team who work with dietitians, as it may illuminate dietitians' roles and expectations regarding decision-making.

1.4 Thesis structure

This introductory chapter has introduced the research by considering the symbolic nature of food and the need for nutrition support. It has also considered my interest in the topic area, and why dietitians' experiences of involvement in decisions about ANH in adult nutrition support are important to explore. This will be further developed in Chapter 2. The structure of the remainder of the thesis is as follows:

The second chapter will provide a background to the research, to set it in context. It will consider the professional guidance regarding dietitians' involvement in decisions about ANH, and consider why decisions can be complex, difficult, and emotive.

The third chapter reviews the literature related to this research. It explores the current evidence base with regard to what is known about dietitians' involvement with ANH and their involvement in decisions about ANH, in order to highlight gaps in the literature. As the literature about dietitians is sparse, the literature review then broadens to consider other healthcare professionals' experiences of involvement and experiences of decisions about ANH. As ANH in dementia is a topic which has been widely researched and debated, it was chosen as one of the main clinical areas to review, to provide a good evidence base which would inform my research. The reviewed literature raised a number of professional practice issues, so literature on the areas of emotional labour, advocacy, and

sociology of professions is also reviewed. Chapter 3 concludes by stating the aim and objectives of this research.

The fourth chapter explores the methodology used in this research.

Methodology should be guided by the research question, in this case 'What are dietitians' experiences of being involved in decisions relating to ANH?' Therefore, Chapter 4 will justify using a qualitative methodological stance, and why I believe interpretive phenomenology was the best approach to address the research question. The procedures used will be described and justified to explain the sampling and recruitment, the data analysis, and my positionality and reflexivity as a researcher. How ethical standards were maintained and how the methods were congruent with interpretive phenomenology will also be explored.

Chapters 5, 6, and 7 are the findings chapters. These describe the three main themes which emerged from the interviews with dietitians about their experiences of involvement in decision-making about ANH for adults.

Chapter 5, 'So much more than just deciding on a feed', describes the varied roles that dietitians adopted during their involvement in decisions, namely the roles of experts, educators, advocates, and technicians.

Chapter 6, 'Wanting to be heard', elucidates the range of experiences from appearing to be heard during discussions and having an involvement in decision-making about ANH through to appearing not to have an influence or be heard during decision-making. The majority of dietitians expressed that they were not heard from time to time.

Chapter 7 explores the findings related to the emotional aspects of involvement in decisions related to ANH. This chapter describes the varied emotions, positive and negative, in the dietitians' accounts. These included pride in doing a good job, anger, guilt, feeling unsure and uneasy about decisions, and moral distress. It then goes on to discuss how dietitians responded to their emotions. These included not showing emotions, keeping a distance from the emotional situation, becoming hardened or blasé, speaking out about the injustice they believed had occurred, and the need for support.

Chapter 8 discusses the three themes with reference to the literature and dietetic practice. The accounts of experiences are considered within the conceptual framework of professionalism and the challenges to dietitians' professionalism.

The final chapter will summarise the research and draw conclusions. The strengths and limitations of the research will be considered, along with the originality and contribution to knowledge this research has made.

Implications for practice, training, the British Dietetic Association, and for further research are suggested.

Some of the terminology used in this thesis has been influenced by the literature and by the accounts of the participants. The term ANH has been used rather than the more recent term 'clinically assisted nutrition' as it is

commonly used in medical and dietetic literature. The participants referred to 'patients' rather than using other terms such as 'clients', therefore 'patient' is the term I have used.

Chapter 2: Background to the study

2.1 Introduction

To set the context for this research and to further justify that exploring dietitians' experiences of involvement in decision-making about artificial nutrition and hydration (ANH) is worthy of research efforts, this chapter will briefly discuss the legal aspects of providing ANH and then explore whether guidelines recommend the involvement of dietitians within decision-making. As it is dietitians' experiences which are being explored in this research I will then go on to consider why decision-making might be complex and troubling for all those concerned, including dietitians.

2.2 Guidance for decision-making about artificial nutrition and hydration in adults

Exploring the legal and professional guidance about ANH can be helpful to set the context of decision-making, but first a definition of ANH is needed. ANH is a common medical treatment which aims to provide nutrition via a tube directly into the gut or into a vein to meet the nutritional requirements of patients who are unable to meet their needs by eating and drinking. This may be a supportive treatment until normal feeding can resume, enabling someone to recover from a specific condition, or it may be a long-term treatment in a chronic condition. In many cases ANH is life-sustaining. A working and accessible gut should be used for feeding if possible. Briefly, tubes which go down the nose into the stomach (naso-gastric (NG) tubes) or into the small bowel (naso-jejunal tubes) may be used for short-term feeding. In the longer term, percutaneous endoscopic gastrostomy

(PEG) tubes, which are inserted via endoscopy, are commonly used. Gastrostomy tubes can also be inserted surgically or with X-ray guidance (radiologically inserted percutaneous gastrostomy). Parenteral feeding into a vein requires a specialist intravenous line which, in some cases, may be provided long term (National Institute for Health and Clinical Excellence, 2006).

English law states that artificial nutrition and hydration should be considered a treatment rather than basic care (Airedale NHS Trust v Bland, 1993), and it is interesting to note that the General Medical Council uses the term 'clinically assisted nutrition' in their latest end-of-life care document (General Medical Council, 2010). This is a change from their 2002 document on withholding and withdrawing treatment (General Medical Council, 2002). While this term does more accurately reflect the medical nature of the treatment, as previously stated, the term ANH will be used in this thesis as it is more commonly used in medical and dietetic literature.

To set the context for dietitians' experiences of involvement in decision-making about ANH, it is helpful to review whether the guidance about decision-making related to ANH does identify dietitians as having a role. Therefore, the focus of this section is not what the guidance says about the technical aspects of providing ANH, for example, minimising the risk of refeeding syndrome, but whether there is a role for dietitians at all in decision-making about ANH. Therefore, I will start by considering the

guidance available about decision-making for ANH aimed at doctors. I will then review the guidance for UK dietitians which outlines their responsibilities within decision-making in general. Where possible, UK guidance has been used; however, as UK dietetic guidance is limited, guidance from America where dietetic practice is similar has been used.

2.2.1 Potential roles for dietitians in decision-making about ANH

As ANH is a medical treatment, informed consent is needed from competent patients for the treatment to be provided. It is assumed that patients have capacity to make a decision unless it can be proved otherwise (Department of Constitutional Affairs, 2005). The General Medical Association (2008) states that ethical decision-making requires competent patients to be provided with information on which to inform their decision-making. Therefore, patients need to be informed of the short- and long-term risks and benefits of ANH as part of the consent process. As nutrition experts dietitians are ideally placed to provide information about the short- and long-term benefits and risks of ANH (Peregrin, 2002; Baird Schwartz, 2013; Brantley *et al.*, 2014; Schwartz, 2015).

Professional guidance for doctors produced by the General Medical Council discusses decision-making in general. The guidance states that doctors should involve other healthcare professionals in discussions with patients as appropriate (General Medical Council, 2008). Doctors should ensure that healthcare professionals can contribute to decision-making (General Medical Council, 2012), and doctors should involve healthcare

professionals and those close to the patient in decision-making if the patient does not have capacity (General Medical Council, 2008). In end-of-life care, the General Medical Council states that healthcare professionals should be contacted if they have relevant knowledge and experience which can help in treating the patient (General Medical Council, 2010). While these statements are not specifically related to the provision of ANH, within the context of ANH it suggests that dietitians have the potential to be involved in the decision-making process as part of the multi-disciplinary team, as they may have developed a relationship with the patient and/or carers and are experts in nutrition.

National Institute for Health and Care Excellence (NICE) guidance on adult nutrition support (2006) recommends that all acute hospital trusts should have a nutrition support team, which may include a dietitian. They also recommend that nurses should work alongside dietitians to reduce complications, train staff, support adherence to nutrition support protocols, and coordinate the transfer of patient care between acute and community settings. The guidance also recommends that dietitians support patients receiving ANH in the community. Additional guidance from NICE (2011b) on end-of-life care for adults recommends advance care planning. This allows for patient involvement in decision-making in the early stages of an illness. These may include decisions about the provision of ANH (Lambert, 2012).

American guidance about gastrostomy feeding towards end-of-life or for those with dementia (Schwartz *et al.*, 2014) also advocates advance care planning, with team collaboration identified as being important. As dietitians may have early and prolonged contact with patients who have progressive conditions, and who may wish to make advance care plans, it has been noted that dietitians have the potential to be involved in advance care planning (Baird Schwartz, 2013; Schwartz, 2015). While not specifically naming dietitians, Lambert's (2012) discussion paper makes the case for allied health professionals being involved in advance care planning because they often have prolonged contact with patients and often develop trusting relationships with them. They are also likely to have a good evidence-based understanding of the risks and benefits of treatments within their field of expertise. Mitchell and Dale (2013) are of the view that advance care planning 'is the responsibility of every healthcare professional who meets the patient' (Mitchell and Dale, 2013:1). Therefore, it might be expected that this would include dietitians in some situations.

Dietitians have been noted as having a role in decision-making for patients with dysphagia. The British Geriatrics Society (Chakladar, 2012) has produced guidance regarding the management of dysphagia which recommends that advice should be sought from dietitians, and they should be involved in the team decision that is made. The guidance suggests that while the focus for feeding should be comfort rather than risk, trials of ANH may be considered.

The American guidance (Schwartz *et al.*, 2014) about gastrostomy feeding towards end-of-life or in those with dementia includes a collaborative algorithm for decision-making which includes the role of a dietitian, such as assessing the patient and liaising with the multi-disciplinary team and carers or surrogate decision makers. The guidance recommends that decision-making should be collegial, and include dietitians (as well as other members of the multi-disciplinary team).

2.2.2 Guidance for dietitians about decision-making in ANH

The British Dietetic Association's code of conduct states that 'it is your duty to ensure that your practice is evidence based, wherever possible' (The British Dietetic Association, 2008a:19). Therefore, to set the context for decision-making about ANH, it is helpful to review the guidance available for dietitians to inform their practice.

Specific UK guidance for dietitians about the provision of ANH is lacking, but there are similarities between British and American dietetic practice, therefore exploring American guidance has relevance. The Academy of Nutrition and Dietetics has produced a position statement for American registered dietitians, detailing the ethical and legal issues of ANH (O'Sullivan Maillet *et al.*, 2013). As American law can vary from state to state, they outline general principles: that patients can refuse ANH (if they have capacity) as it is a medical treatment, and that dietitians should be working with the wider team when decisions are made about withdrawing or withholding ANH.

In 2006 NICE produced guidance on nutrition support in adults (National Institute for Health and Clinical Excellence, 2006). This guidance includes considerations about withdrawing ANH. The guidance recommends the use of trials of ANH when it is not clear whether ANH will be of benefit, that is, feed, then review the situation after a set time, and then decide to continue or withdraw feeding. The guidance does note that in clinical practice it can be harder to withdraw ANH than withhold it. The guidance from the Royal College of Physicians (2013) encourages good communication and family involvement in end-of-life planning so that relatives do not feel that the medical team are giving up on the patient if treatment is withdrawn.

The British Association for Parenteral and Enteral Nutrition (BAPEN) has produced 'Standards and Guidelines for Nutritional Support of Patients in Hospitals' and 'Ethical and Legal Aspects of Clinical Hydration and Nutritional Support' both of which were updated in December 2012; however, the full documents are no longer available on the BAPEN website. As an alternative, BAPEN has used these and other guidelines with professional consensus to produce practical guidance via decision trees on the diagnosis and management of problems with PEGs, the ethics of ANH at end-of-life, inserting NG tubes, perioperative nutrition, and identifying those at risk of refeeding syndrome (Cooper, 2012). BAPEN acknowledges that decision-making can be difficult in some patient groups, hence the development of their 'decision trees' to help with nutritional decision-making (Cooper, 2012).

2.3 Professional guidance for dietitians about decision-making

Guidance from professional and regulatory organisations recognises the dietitian's role in decision-making in general, and they have produced guidance for dietitians to inform this area of their professional practice. The Health and Care Professions Council's standards and codes of conduct both include consideration of decision-making (Health and Care Professions Council, 2013; Health and Care Professions Council, 2016). These recognise dietitians as autonomous professionals who need to make informed, reasoned, justifiable decisions for which they are personally responsible. Dietitians need to provide patients with information to help them make informed decisions. They also need to ensure that decisions are documented and shared with other healthcare professionals as appropriate. The standards make it clear that decisions should be in the patient's best interests and that dietitians should have an understanding of the ethical and legal implications of withholding and withdrawing ANH (Health and Care Professions Council, 2013; Health and Care Professions Council, 2016).

The British Dietetic Association's (2013) guidance on decision-making is partly addressed in their curriculum for pre-registration education, and training. This states that new graduate dietitians should take personal responsibility for professional decision-making, should be able to justify the reasoning for their decisions, should use evidence as well as patient values to inform their decisions, and should involve patients in decision-making. This and other British Dietetic Association guidance recognises

advocacy as part of professional practice and that ethical dilemmas should be recognised and managed with support (The British Dietetic Association, 2010; The British Dietetic Association, 2013).

2.4 Complex and troubling decisions about artificial nutrition and hydration

With all research it is important to consider the broad context to show that it is worth undertaking. Therefore, as it is experiences which are being explored, I will now consider why decision-making about ANH might be complex and troubling. To set the scene for this discussion, I will first briefly recap on some of the points made in this thesis so far. I have outlined that food and nutrition are associated with caring and nurture, and that not providing nutrition can be more troubling for those caring for the patient than for the patient themselves. The UK has an ageing population, so it is likely that chronic diseases and ill health will increase, which may result in more difficult decisions about ANH. Consent is needed before ANH is provided. If patients lack capacity for decision-making about ANH, best interests decisions need to be made. Finally, ANH is a medical treatment, so it can be withdrawn or withheld. How these issues all contribute to complex decisions will now be considered.

Before a decision is made about whether to offer ANH as a treatment option, the multi-disciplinary team should make a judgement about the potential benefit of the treatment. It might seem logical to provide ANH if someone was malnourished or at risk of malnutrition if they were unable to maintain an adequate intake orally, but not providing ANH is sometimes

the right course of action (British Medical Association Medical Ethics Committee, 2007). Therefore, these decisions may not be as straightforward as it might first appear. Assessment needs to extend beyond the feed just providing biological fuel and meeting a patient's nutritional requirements: the healthcare team need to consider whether the ANH provides a clinical benefit. For example, will it help to improve an underlying condition? Shannon (2006) cautions against just fuelling a body through ANH, as without an improvement in condition it will only prolong dying.

Nutrition support may improve outcomes in some clinical conditions (Stratton and Elia, 2007), but not all. For example, some types of pre-operative nutrition support reduced total post-operative complications in patients undergoing gastrointestinal surgery (Burden *et al.*, 2012), and early nutrition support improves quality of life and the rate of weight loss in upper gastrointestinal cancer (Silvers *et al.*, 2014). While the view has been challenged (Regnard *et al.*, 2010), it is generally accepted that in end-stage dementia there is no benefit in providing ANH in terms of survival (Goldberg and Altman, 2014) or improvement in nutrition status (Sampson *et al.*, 2009; American Geriatrics Society Ethics Committee and Clinical Practice and Models of Care Committee, 2014). In adult palliative care there is no evidence of a benefit of ANH (Good *et al.*, 2014).

Less clear-cut is the evidence regarding motor neurone disease. An evidence-based review of ANH in motor neurone disease concluded that while ANH via a PEG can help to stabilise weight, and may prolong life, it

is not clear that it improves quality of life (Miller *et al.*, 2009). Good practice in decision-making suggests that this information should be shared with patients in order for them to balance possible reduced quality of life with prolonging life. It is likely that an individual's assessment of this will vary and may be influenced by their personal values. Some may prioritise quality of life, while others may prioritise sanctity of life, which aims to extend life where possible. Due to these personal values and beliefs an individual's decision may be different to the opinion of healthcare professionals, which may lead to conflict or difficulty for the healthcare professionals, including dietitians.

The evidence is also mixed within stroke research. Early tube feeding is recommended post-stroke for those with dysphagia (Royal College of Physicians Intercollegiate Stroke Working Party, 2012). However, there is evidence that it might lead to greater long-term disability and the need for long-term ANH (The FOOD Trial Collaboration, 2005).

An assessment of the burden of ANH also needs to be undertaken, and a judgement made as to whether the burdens outweigh the benefits. Again, this is not as easy as it might first appear. There are small but significant risks associated with ANH such as diarrhoea, aspiration pneumonia, and infection (Armer and White, 2014). It is also important to consider the longer term burdens of ANH such as its effects on quality of life. During the early stages of a patient's illness, a judgement may be made that the benefits of ANH outweigh the burdens, as it may be thought that the

patient may improve. However, over a longer term the benefit-to-burden ratio may change. Indeed, the evidence is mixed about the quality of life of patients receiving long-term ANH and it will vary depending on diagnosis (Kitzinger and Kitzinger, 2014a).

The General Medical Council recommends that if there is an overall benefit to treatment it should be provided (General Medical Council, 2010). However, the same guidance does give an indication of some of the complexities and difficulties of ANH towards the end-of-life, for example, that suffering may be experienced if ANH is not provided, but the provision of ANH may itself cause suffering and prolong dying (General Medical Council, 2010). The British Dietetic Association's (2008a) code of conduct states that dietitians should provide information to patients in a form they can understand to help with decision-making, therefore given the complexities outlined, this may be a challenge for dietitians.

If ANH does not have clinical benefit and/or the burdens outweigh the benefits, ANH may be considered futile. This is important because a medical treatment does not have to be provided if it is futile, so it can be withheld or withdrawn. An indication of the number of people who might be receiving futile ANH has been provided by the National Confidential Enquiry into Patient Outcome and Death, who suggested that 19% of PEG tubes were considered futile or not indicated (Cullinane *et al.*, 2004). Providing futile care has been reported as being difficult and troubling for the nurses involved (Bryon *et al.*, 2010). It is not known if dietitians have

similar experiences. Discussions about futile care may lead to decisions about withdrawing or withholding ANH which may be related to end-of-life situations if ANH is a life-sustaining treatment. Casarett (2005) and Monturo (2009) note that these decisions are difficult to make, and others highlight the emotive element to these decisions (Modi *et al.*, 2010; O'Sullivan Maillet *et al.*, 2013). Some relatives and healthcare professionals, including Irish dietitians, seemed to be troubled by withdrawing ANH, as they view such decisions as 'starving' patients (Healy and McNamara, 2002; Whitworth *et al.*, 2004; BBC, 2008; Kitzinger and Kitzinger, 2014a). Therefore, the experiences of UK dietitians are important to explore, to see if they too are troubled by these situations.

A patient's wishes must be taken into account during decision-making about ANH, as they may not wish to receive ANH and can refuse ANH if they have capacity to do so, even if the healthcare team believe treatment would be of benefit. Of course, patients need to be given accurate information on which to inform these decisions and UK research suggests that this is often lacking (Liley and Manthorpe, 2003; Brotherton *et al.*, 2007b; Brotherton *et al.*, 2007c; Vesey *et al.*, 2008; Brotherton and Abbott, 2009). A report from the British Association for Parenteral and Enteral Nutrition (Elia and Wheatley, 2014) recommended that healthcare professionals communicate clearly with patients, discussing and agreeing treatment goals with them directly, as the patient's goals may be different to the goals of healthcare professionals. Some authors have made recommendations that: more time should be available for decision-making;

there needs to be improved communication between patients/carers and the team; and there needs to be improved communication within the teams, which should enable patients to participate in decision-making (Vesey *et al.*, 2008; del Río *et al.*, 2012). It has also been recommended that healthcare professionals work with patients to help to improve patients' involvement in decision-making by helping them understand why ANH might be needed (Orrevall *et al.*, 2004; Mayre-Chilton *et al.*, 2011; Hogden *et al.*, 2012). Dietitians are ideally placed to contribute to many of these recommendations, given their knowledge of the benefits and risks of ANH and their roles in information giving. However, whether they are involved in this way and what their experiences are have not been explored until now.

Religious and spiritual aspects add another dimension to complex decision-making about the provision of ANH. For example, while in the UK ANH is classed as a medical treatment, the Catholic Church views ANH as basic care (John Paul II, 2004). Therefore, as basic care, the Catholic Church believes that ANH should be provided except in exceptional circumstances (The Congregation for the Doctrine of the Faith, 2007), although this view is debated by religious scholars (Clark, 2006; Drane, 2006; Harvey, 2006; O'Rourke, 2006; Shannon, 2006; Nowarska, 2015). Brett and Jersild's (2003) case study paper outlines the four main religious convictions which some American Christian patients and families use as motivations for requesting medical care such as ANH. These are: a belief in a miracle; refusing to give up on having faith in God; sanctity of life; and

suffering has a redemptive value. Belief in a miracle and sanctity of life were also factors which led to conflict in decision-making among some relatives of varied faiths (Protestant, Muslim, Jewish and Roman Catholic) in the setting of a British paediatric intensive care unit (Brierley *et al.*, 2013). The religious beliefs of the healthcare team have also been shown to have an influence on the provision of ANH (Wolenberg *et al.*, 2013). Again, little is known about dietitians' experiences of this.

Consent can also be a complex area of decision-making. The Mental Capacity Act (Department of Constitutional Affairs, 2005) assumes that patients have capacity unless it is shown otherwise; however, this can be hard to judge in some patients, therefore it can be difficult for a dietitian to know whether the decision made is really what a patient wants. Rahman *et al.* (2012) reviewed the mental capacity of patients undergoing PEG in a UK hospital. The researchers assessed whether the medical team's assessment that a patient had capacity was correct, and reported that in 31.5% of assessments patients were incorrectly assessed as having capacity. They concluded that 74% of patients undergoing a PEG did not have capacity, but it could be as high as 82% not having capacity to consent. However, the authors did state that there was no evidence to suggest that the PEGs were not indicated (Rahman *et al.*, 2012). The National Confidential Enquiry into Patient Outcome and Death (Cullinane *et al.*, 2004) also noted concerns about consent. These concerns related to patients who had dementia or acute confusion but who had still provided 'written consent' for a PEG to be inserted (Cullinane *et al.*, 2004).

This might have implications for the professionalism of dietitians, as professional codes of conduct state that patient's autonomy should be protected (The British Dietetic Association, 2008a; Health and Care Professions Council, 2016).

The involvement of families in decisions is important in some situations. When a patient is unable to express an opinion, those close to the patient may be involved in the judgement of whether a patient's quality of life is acceptable (General Medical Council, 2010). If patients are unable to express their own views, relatives should be consulted to obtain a view of what their family member might have wanted (General Medical Council, 2008). However, there is a risk that family members may not accurately report the views or beliefs of their relative. A qualitative German study found that the majority of family members of patients with persistent vegetative state based their decision on their own feelings, and not what they thought their family member wanted (Kuehlmeier *et al.*, 2012). Haddad (2004) suggests that 50% of the time relatives' decisions are different to those that the family member would make.

The involvement of families in decision-making can be burdensome for relatives. Both Drane (2006) and Weissman (2000) describe family involvement in decisions about providing ANH to incompetent patients as being the most troublesome decision that families make. Van Rosendaal and Verhoef (1999) likened this to deciding that a loved one will die (Van Rosendaal and Verhoef, 1999). Van Rosendaal *et al.* (1997) suggest that

because of a decision to insert a PEG '[P]erhaps we sometimes provide a lingering death, because we have not met the needs of patients and their families in the process of high-stakes, high-stress decision-making' (Van Rosendaal *et al.*, 1997:2). Weissman (2000) suggests that doctors need to take greater leadership in these situations to guide the families to consider their loved one's values, in order to come to a suitable and compassionate decision. Within the UK, it is the medical team, with the patient (if they have capacity), who have the ultimate responsibility for decision-making. While they may consult families about what their family member might have wanted, it is the doctors and not the family that make the decision. However, medical teams have been criticised for not supporting families in these situations, as families often feel responsible for the difficult decisions made by the team (Kitzinger and Kitzinger, 2014b). Overall this can be challenging for the health professionals involved in decision-making.

Some decisions about ANH have to be made by the High Court; for example, when patients have a prolonged disorder of consciousness, or where there is conflict between the medical team and the family, or where there are disagreements about the capacity for decision-making (British Medical Association Medical Ethics Committee, 2007). The decision by the High Court (*W v M*, 2011) not to allow the withdrawal of ANH from a patient in a minimally conscious state has been widely debated (Heywood, 2012; Glannon, 2013; Sheather, 2013; Chan and Tipoe, 2014) highlighting the complexity of such difficult decisions.

2.5 Summary

This chapter has reviewed the guidance on decision-making about ANH in adults and has highlighted the potential roles dietitians may have in decision-making based on that guidance. The professional guidance for dietitians on decision-making in general has also been reviewed, which indicates that dietitians are expected to have a role in decision-making. The complex, difficult and troubling nature of decision-making related to ANH has also been outlined. These factors provide a background to the potential involvement of dietitians in decision-making about ANH and that their involvement might be difficult. As this is an area not researched before now, this chapter contributes to the justification for exploring dietitians experiences.

In the next chapter this thesis will review the literature in the area to further justify this area of study.

Chapter 3: Literature review

3.1 Introduction

The previous chapters introduced the symbolic position of food, discussed how decisions about the provision of artificial nutrition and hydration (ANH) can be complex and troubling, and that ANH is a treatment that can be withheld or withdrawn. It briefly explored what ANH is and that dietitians are autonomous practitioners who should be involved in decision-making. The research question guiding this research is 'What are dietitians' experiences of being involved in decisions relating to ANH?' Therefore, the initial focus of this literature review will be decision-making within ANH.

This literature review aims to explore what is known about dietitians' experiences of decision-making related to ANH, therefore this forms the first section of this literature review. However, as there was only a small amount of literature retrieved about dietitians' experiences about ANH, the literature search needed to be widened. To do this I looked for research exploring experiences of other healthcare professionals who are involved in decision-making about ANH; that is, doctors, nurses, and speech and language therapists.

As I reviewed some of this literature on healthcare professionals' experiences, it became clear that decisions around feeding in dementia were a common feature. This seemed to be an area I should consider further. Therefore, I took the decision to focus on ANH in dementia, as the empirical literature base could illuminate the complexity of decision-making

about ANH and also included experiences of healthcare professionals. ANH is sometimes considered in patients with dementia, as feeding and swallowing problems are common and decision-making is often difficult because patients frequently do not have the capacity for decision-making. Additionally, these decisions are sometimes end-of-life decisions, which gives an added complexity. In this patient group there can be challenges of deliberating about previously expressed wishes versus current wishes as perceived by healthcare providers and family. These complex situations share features with decision-making about ANH in other clinical conditions, such as a stroke or progressive neurological conditions where capacity is lacking, and the complexity of considering risks and benefits of ANH, which is required for all decision-making. Therefore, dementia was considered a suitable focus for the literature review. However, in order not to narrow the literature review, and risk excluding literature which may be of value to inform my research I also included research of nurses' experiences of involvement in decisions about ANH.

The literature was searched using a number of databases. A full search strategy is shown in Appendix 1, but briefly the search terms for ANH were:

(Artificial nutrition OR artificial hydration OR intravenous fluid OR tube feeding OR PEG OR nasogastric tube OR percutaneous endoscopic gastrostomy OR hyper alimentation OR clinically assisted nutrition OR enteral feeding OR enteral nutrition OR parenteral nutrition). These were combined with AND (experience OR beliefs OR attitudes). They were also

combined with AND (decision making OR decision-making). The additional terms for dietitian (dietitian OR dietician) and dementia (dementia OR Alzheimer's disease) were used as required.

3.2 Dietitians and decision-making about artificial nutrition and hydration

This literature review will start with dietitians and decision-making related to ANH. While dietitians' experiences of decision-making have not been researched (outside this study), there is some empirical research with dietitians relating to other aspects of ANH, such as what decisions dietitians report they would make in a hypothetical situation and if they believe they have a role in decision-making about ANH. The reviewed studies surveyed dietitians from America, Canada, the UK and Ireland to obtain the views of large numbers about whether to feed a patient or not (Wall *et al.*, 1991; Taper and Hockin, 1996; Healy and McNamara, 2002; Langdon *et al.*, 2002; Enrione and Chutkan, 2007). The researchers used Likert scales (generally 'strongly agree' to 'strongly disagree') to obtain dietitians' views of whether they would provide ANH in a given scenario or vignette.

There was a general view that when there was a doubt about if ANH should be provided, it should be started or continued (Healy and McNamara, 2002; Enrione and Chutkan, 2007). Studies also indicate that dietitians seemed to be more willing to stop providing ANH if it seemed to be harming the patient, if death was imminent, if the patient requested it be stopped (Wall *et al.*, 1991), or if the patient was in a persistent

vegetative state (Healy and McNamara, 2002). They were also more likely to stop invasive feeding, such as total parenteral nutrition compared to enteral nutrition (Wall *et al.*, 1991).

Patient autonomy was an aspect of a number of studies. The American survey of 478 dietitians conducted by Langdon *et al.* (2002), reported that most of the dietitians surveyed agree that a patient can refuse ANH, that ANH can be withdrawn, and that ANH should not be used in every case. However, 8% of dietitians surveyed felt that patients should not be allowed to refuse ANH and 18% felt that it was not acceptable to remove nutrition support even for patients who are at the end of their life. A difference in views was identified based on the age of the dietitians, the years of clinical practice, and the area of work. Dietitians over 45 years old were more likely to disagree with removing end-of-life nutrition support than a younger dietitian, those practising for more than 20 years were more likely to disagree with end-of-life nutrition support removal than those who had been practising for less than 10 years, and dietitians working in the community were more likely to disagree with removal of nutrition support than those working in other clinical areas.

Enrione and Chutkan's (2007) survey of 499 American dietitians noted similar findings, with 25.1% of the total reporting that they did not agree that 'a generally healthy older adult, if competent, has the same right to decline ANH as a competent person who is terminally ill' (Enrione and Chutkan, 2007:418). Of those surveyed, 8% felt that patients should receive

nutrition support regardless of the patient's wishes. Enrione and Cutkan (2007) also found that dietitians were more likely to err on the side of caution in their treatment, with 73.2% of the dietitians agreeing with the statement 'when in doubt, feed' (Enrione and Chutkan, 2007:418).

Taper and Hockin (1996) surveyed 1,724 Canadian dietitians about their ethical beliefs. They investigated how the dietitian's ethical beliefs influenced care judgements related to withholding or withdrawing ANH. The authors suggest that the results indicate that 95% of dietitians use a framework which valued ethical discourse and dietitians have a role in ethical decision-making. Most (75%) included patient autonomy in their framework. Just over half of the surveyed dietitians (51%) would accept the removal of ANH in terminally ill elderly patients. Some dietitians (23%) accepted that their ethical framework was influenced by their religious values. These findings suggest that dietitians use a range of different values to inform their decision-making.

The attitudes of 148 UK healthcare professionals (45 geriatricians, 7 speech and language therapists and 71 nurses) and 25 dietitians to percutaneous endoscopic gastrostomy (PEG) insertion in elderly patients was investigated by Hasan *et al.* (1995). Broadly, professions agreed with PEG insertion in this population, even in patients with long-term dementia. Quality of life was the most important factor influencing a decision for ANH in the population surveyed. The majority of subjects (64%) believed that decisions were reached by the multi-disciplinary team rather than just the

doctor. This study was published in 1995 when PEG insertion was just starting to become common in the UK. The use of ANH and PEG in advanced dementia is now a widely debated topic, but generally it is accepted that the harms outweigh the benefits (Gillick and Volandes, 2008; A.S.P.E.N. Ethics Position Paper Task Force *et al.*, 2010; American Geriatrics Society Ethics Committee and Clinical Practice and Models of Care Committee, 2014; Volkert *et al.*, 2015).

In a slightly different type of original research, Luby *et al.* (1991) conducted a survey to assess the moral reasoning of American dietitians compared to American nurses related to withholding and withdrawing ANH. While there was no difference in the principled morality score of nurses and dietitians, the authors conclude that more education on ethics would improve the moral reasoning skills of dietitians.

In Ireland a survey of 63 dietitians was conducted by Healy and McNamara (2002). It used a self-administered questionnaire using case scenarios to assess how dietitians deal with nutrition support in 'controversial patients' (Healy and McNamara, 2002:445), that is, patients with end-stage dementia and patients in a persistent vegetative state. The dietitians were asked if they had been involved in decisions about ANH for patients with advanced dementia and to what degree they were involved in the decision-making process.

Healy and McNamara (2002) reported that 41% of respondents (n=63) were involved in starting or stopping ANH in patients with dementia. Of these, 30% (n=19) felt that they were not adequately involved in the decision-making process and 24% (n=15) were unsure of their influence. Some 9% (n=6) reported that they felt they had no influence on the care plan of patients with dementia. The surveyed dietitians identified information giving and communication to be problems; 67% (n=42) believed that information given to families or other decision makers was inadequate and 58% (n=89) believed that communication among the medical team about ANH in dementia was insufficient. When commenting on their treatment decisions about ANH for a patient with end-stage dementia, 49% would provide ANH and 50% would not. The reasons given for feeding were the belief that withholding ANH would cause starvation, it would be unethical, inhumane, and a form of neglect. For those who would not provide ANH, the reasons reported were that the patient's quality of life was unlikely to improve and that if a patient refuses to eat they do not want to live. Similar results were reported for a patient with persistent vegetative state, with 48% of respondents in favour of continuing with ANH in someone with persistent vegetative state and 47% opposed to feeding.

Finally, Szeto *et al.* (2014) surveyed 67 Canadian dietitians about their roles in decision-making for PEG placement in elderly patients. Of those who responded, 97% reported that they thought dietitians had a role in decision-making about PEGs; however, only 87% indicated they

participated in decisions. Approximately 13% reported that they always took part in decisions about PEG in elderly patients, 34.3% usually, 26.9% occasionally, 11.9% rarely, and 13.4% reported that they never took part in decisions about PEG. Dietitians' involvement in decision-making was greater when they had a positive relationship with doctors ($p=0.016$), when they felt they had adequate knowledge ($p<0.001$), and when they felt they had adequate skills ($p<0.001$). However, the nature of the knowledge and skills was not indicated. Involvement in decision-making resulted in them reporting to feel more satisfied with their role ($p<0.001$). The authors concluded that involvement in decisions and involvement with patients and families was increased by having a good working relationship with physicians, good knowledge, and skills.

The findings of the survey by Szeto *et al*, (2014) revealed if dietitians reported to being never, rarely, occasionally, usually, or always involved in a pre-defined role. The results for the combined categories of usually or always are presented here to give an indication of the roles the dietitians reported that they undertook. The survey results indicate that with patients or carers the most common roles were to identify nutritional issues (91.2%), discuss feeding options and alternatives (80.7%), discuss issues of hunger, thirst, and dry mouth (59.5%), and discuss the benefits of PEG (50.9%). Less common roles with patients and carers were to discuss the outcomes of PEG with the patient or family (49.2%), discuss PEG with the patient or family (49.1%), discuss the risks (43.9%), patient preferences (40.4%), assessing patients' competence (40.3%), describing PEGs to the

patient or family (35.1%), and to discuss the physiological adaptations at the end-of-life (21%).

With doctors and other members of the healthcare team, the survey results indicate that the roles always or usually reported as being undertaken were discussing the option of PEG with the healthcare team (73.7%) and discussing the option of PEG with the physician (56.2%), while 49.2% reported that they assisted physicians in providing information, advice, and guidance to patients. This study reported the varied roles that dietitians self-report, but does not indicate the detail of what the role entailed. However, it does highlight that 10% of dietitians who believed that they should be involved in decisions about PEGs were not involved, and 38.8% were only rarely or occasionally involved.

While these studies broaden the evidence base, they have limitations. A survey study design is open to non-responder bias. Some of these studies had excellent response rates (Taper and Hockin, and Langdon had 72% and 62% respectively) while other studies had a poor response rate, leaving them open to non-responder bias. (The response rate for Enrione and Cutkan was 36.2%, Wall was 42%, Healy and McNamara was 45%, and Szeto 16.9%.) The sample size of the surveyed dietitians was varied ranging from just 67 to 2408 dietitians. This enabled a range of ages, clinical areas, and years of experience, increasing the external validity of some of the surveys. Not all important characteristics were considered in some surveys. For example, there was no assessment of whether religion

influenced the decisions of the Irish dietitians in Healy and McNamara's (2002) study. This was an influencing factor for the Canadian dietitians in Taper and Hockin's (1996) survey. The use of Likert scales and vignettes/case scenarios in these studies can also be problematic, as the patient scenarios or vignettes lack detail, and many of the decisions will depend on the whole clinical and social picture. Vignettes can lead to a simplification of responses (Hughes and Huby, 2002) and do not capture the emotional experiences of decision-making (Torke *et al.*, 2008), especially if used in a quantitative study which does not allow for experience to be captured. There is also a risk that respondents may give replies which conform to expected norms.

There is a paucity of research about dietitians and decision-making in ANH, and much of the research that does exist was conducted 15-20 years ago, when it could be argued that dietetic practice was different as dietitians were not considered to be autonomous practitioners (Judd, 2011). The research showed that dietitians did think ethically when making decisions and reported that dietitians had a varied amount of influence on the decision-making process. Some dietitians would not be willing to stop ANH in some patients regardless of patient wishes, with some suggesting that withdrawing ANH was unethical. Often the findings were polarised, with half the respondents being in favour of feeding and half against. Dietitians report that they take on varied roles during the decision-making process about PEGs, but not all the dietitians who believed that they had a role in decision-making reported being involved. The majority of this

research was also conducted with dietitians who practised in other countries. While there are similarities in the practice of dietitians in America, Canada, and Ireland, their healthcare systems are different which will influence the external validity of the reported findings.

None of the reviewed literature captures the actual 'lived experiences' of dietitians who were involved in decision-making related to ANH, and the emotions related to being involved with these complex situations. Therefore, research with other healthcare professionals will now be reviewed.

3.3 Experiences of healthcare professionals' involvement in decision-making about artificial nutrition and hydration

In my initial searching of the literature about healthcare professionals' experiences of involvement in decisions about ANH, I retrieved a lot of literature in the clinical area of dementia. However, I also retrieved some research of nurses' experiences in the areas of palliative care, stroke, cancer, patients who were seriously or terminally ill, and decisions about PEG for patients with stroke, head injury, head and neck cancer, and motor neurone disease. Therefore, in order not to narrow the literature review too much, I will review this research before focusing on ANH and dementia to give more depth.

The experiences or views of nurses from a range of countries have been reported. Holmdahl *et al.* (2014) interviewed Swedish district nurses about

their experiences of caring for palliative patients receiving parenteral nutrition at home. Tsaloglidou *et al.* (2007) interviewed UK nurses about their involvement in the process of ethical decision-making to start or withdraw ANH. Todd *et al.* (2005) interviewed Canadian nurses about ANH provided via PEGs. Day *et al.* (1995) interviewed American nurses about feeding or withholding ANH from patients with cancer (and dementia, although the dementia data is presented in section 3.4.3.3). Finally, Ma and Yang (2007) used a case study approach to explore the experience of a Chinese home care nurse in helping a patient to decide whether to have a PEG.

Holmdahl *et al.* (2014) reported that the nurses they interviewed felt they needed more support, that they recognised the importance of building relationships with patients in order to have discussions about withdrawing ANH, and that there was a symbolic meaning to the nutrition, of hope and life. The overarching theme summed up the emotive aspect of caring for these patients as ‘the agony of terminating hope’ (Holmdahl *et al.*, 2014:93).

The nurses interviewed by Tsaloglidou *et al.* (2007) wanted to be involved in decision-making about ANH, and to act as patient advocates. However, they felt that due to a lack of knowledge, confidence and experience, they were only indirectly involved in the decision-making process. The authors noted that the nurses did express their views and discomfort with the decisions made to colleagues, but did not express these formally during

the decision-making process. Tsaloglidou *et al.* (2007) suggest that this might be because they did not want to take on the responsibility of the decision.

The process of making decisions to use PEGs was the focus of the research by Todd *et al.* (2005). The nurses interviewed felt that their patients were not given enough information about PEGs and they felt guilty that they did not fully discuss the implications of having a PEG due to time pressures. The nurses also felt that they were not adequately involved in the decision-making process, and this led to feelings of frustration. However, when they were involved, it caused them stress if the decision for a PEG sustained what they believed to be a poor quality of life. When they felt that long-term feeding via a PEG was the wrong decision, they felt sadness and frustration. The nurses who felt supported seemed to cope better with these emotional situations.

Day *et al.* (1995) reported the ethical principles which cancer nurses used during their decision to feed a cancer patient with capacity who refused to eat. Only two nurses (5%) would feed the patient, citing sanctity of life for their motivation; however, they would stop feeding if the patient suffered. The nurses who would not support ANH for the patient cited patient autonomy as their guiding principle. However, some nurses would feed if ordered to do so by a doctor.

Ma and Yang (2007) outlined the support and skills a home care nurse used with a patient during decision-making about PEG insertion. By developing a relationship, providing long-term support and being empathetic, and also by exploring the patient's and family's views of mobility, possible harm and body image, the nurse helped the patient to come to a decision.

All these qualitative studies used interviews to collect rich data, while Tsaloglidou *et al.* (2007) also used observation which provided method triangulation. Day *et al.* (1995) used a vignette of a patient on which to base their discussion, which may be useful for reflection (Torke *et al.*, 2008); however, it may not reflect real practice. The main limitation of all the studies is that the researchers did not adequately consider their own position within the research, although the full research by Ma and Yang (2007) was published in Chinese, so it was just the abstract appraised.

Overall, these studies highlight that nurses wanted to be involved in decisions and act as patient advocates. However, often they were not fully involved in decisions, which led to feelings of sadness and frustration when they did not agree with a decision. Support was important for the nurses. This resonates with the research with dietitians, which reported that dietitians' influence on decisions about ANH were varied, and that they were not as involved as they wished to be. Reports of the possible emotional effects of involvement in decisions are lacking in the research

with dietitians, as until now there has not been any research exploring their actual experiences.

3.4 Artificial nutrition and hydration in advanced dementia

3.4.1 Introduction

As there is limited research about dietitians and other healthcare professionals' experiences of ANH, and dementia was identified as an area which might illuminate some of the complexities of decision-making, the literature review will now broaden to consider healthcare professionals' experiences of involvement and experiences of decisions about ANH in the clinical area of dementia. As previously justified, dementia and ANH was chosen as a clinical area to review as it has been widely researched and debated, and is an area which often includes difficult decision-making about ANH, therefore it may inform my research.

Feeding problems are common in patients with advanced dementia: Mitchell *et al.* (2009) followed up patients with dementia for 18 months and revealed that 85.8% of patients had an eating problem. The American Geriatrics Society position statement about feeding tubes in advanced dementia (American Geriatrics Society Ethics Committee and Clinical Practice and Models of Care Committee, 2014) suggests that careful hand feeding is preferred to tube feeding in advanced dementia.

Despite guidance in this area that tube feeding is not recommended (Royal College of Physicians and British Society of Gastroenterology,

2010; National Institute for Health and Clinical Excellence, 2011a; American Geriatrics Society Ethics Committee and Clinical Practice and Models of Care Committee, 2014; Volkert *et al.*, 2015), patients still receive this intervention, perhaps because of the 'strong emotional and psychological meanings' associated with feeding (Valentini *et al.*, 2014:1143). Ethical issues, such as capacity and lack of advance care planning, complicate decision-making, as does the emotional spectre of starvation. The ethical components of guidelines about dementia have been recently reviewed by Knüppel *et al.* (2013). They concluded that the NICE guidelines did address the ethical issues associated with tube feeding adequately; however, many other countries' guidelines, including SIGN guidelines from Scotland, did not. Clear ethical considerations and the rationale for recommendations contained within guidelines are important for all users of guidelines.

To set the scene about the use of ANH in dementia, the literature review will now continue by exploring systematic reviews about the use of ANH in patients with dementia, and then will go on to explore healthcare professionals' experiences of decision-making about ANH in dementia.

3.4.2 Systematic reviews about artificial nutrition and hydration in dementia

Over the last five years a number of reviews have investigated various aspects of dementia and ANH. The role of ANH in dementia care was evaluated in a review by Brooke and Ojo (2015). A review by Alagiakrishnan *et al.* (2013) explored swallowing problems, their diagnosis

and management in people with dementia. Connolly *et al.* (2012) conducted a systematic review which examined the end-of-life care of people with dementia from ethnic minority groups. Ribeiro Salomon and Carvalho Garbi Novaes' (2015) review aimed to evaluate outcomes in patients with dementia who received ANH at home. Finally, Jaafar *et al.* (2015) reviewed the literature to compare the effectiveness of PEG feeding compared to naso-gastric (NG) feeding in patients with non stroke-related dysphagia, in which four of the nine studies in the review included patients with dementia. Gomes *et al.* (2015) also reviewed the literature which compared PEG with NG in adults with swallowing disturbances. However, their study only reviewed one paper which included patients with dementia, and this paper was also included in the Jaafar *et al.* (2015) review, therefore the Gomes review will not be discussed here.

The review by Alagiakrishnan *et al.* (2013) reported that the prevalence of swallowing difficulties in patients with dementia ranged from 13% to 57%, and the incidence of feeding tube insertions in nursing home residents with advanced dementia was 56/1000. The most common reasons for ANH were aspiration pneumonia, failure to thrive, and dysphagia.

Therefore, at face value ANH may be indicated, although the risks and benefits of ANH also need to be considered during decision-making.

The risks and benefits of ANH in dementia were evaluated in the reviews by Brooke and Ojo (2015), Jaafar *et al.* (2015), Ribeiro Salomon and Carvalho Garbi Novaes (2015) and Alagiakrishnan *et al.* (2013). Brooke

and Ojo (2015) reported a mixed picture of the effect of PEG on mortality. Some studies indicated an increase, some showed a decrease, and some showed no effect. Ribeiro Salomon and Carvalho Garbi Novaes (2015) also showed a mixed picture with some studies reporting higher mortality rates and risk of pressure ulcer development in patients receiving ANH compared to those who were not. Jaafar *et al.* (2015) reported similar findings, and concluded that there was no significant difference in risk of pneumonia or overall complications when comparing PEG with NG feeding. However, there was mixed data for mortality and nutritional outcomes, with some studies favouring PEG over NG tubes.

Alagiakrishnan *et al.* (2013) drew similar conclusions. They found that the use of PEG tubes in advanced dementia (compared to not using them) showed no benefit in terms of survival, improvement in quality of life, or reduction in aspiration pneumonia. In fact, 58% of enterally fed nursing home patients with dementia had aspiration pneumonia compared to 16% of those fed orally at six months ($p < 0.01$). The 30-day mortality rate post-PEG insertion was 54% in the dementia group and 28% for the group that did not have dementia ($p < 0.0001$). Other data reported by Alagiakrishnan *et al.* (2013) suggested that six month mortality was higher in patients who had a PEG tube compared to those with no PEG (44% vs 26%, $p < 0.03$). The 12-month mortality rate was 90% in those who had dementia and a PEG inserted, but 63% in those with a PEG without dementia, with a median survival in dementia of 56 days post-insertion of the tube.

The review by Connolly *et al.* (2012) examined end-of-life care of people with dementia from ethnic minority groups. The authors reviewed the literature to explore any relationships between being in an ethnic minority group and the type of end-of-life care received. They included patients with dementia or severe cognitive impairment, and/or their carers. They included data about the use of ANH, cardiopulmonary resuscitation, mechanical ventilation, admission to intensive care units, palliative care, pain management, and hospice care. They also included data about advance care planning; for example, do not resuscitate orders, do not hospitalise orders, durable power of attorney, living will status, and surrogate decisions. Twenty studies were included in the review, which were a mix of quantitative and qualitative research, but all studies reported findings with American populations. The data on ANH from seven high quality studies is reported here.

Connolly *et al.* (2012) reported that overall there were higher rates of ANH use in ethnic minority groups. African-Americans were between 1.5 and 9.4 times more likely to have received ANH compared to Caucasians. While some studies reported similar use of ANH in Hispanic patients compared to Caucasians, other studies reported Hispanic participants were 1.3-2.7 times more likely to have received ANH. The data for Asian patients suggested that they were 1.5-2.3 times more likely to have received ANH. In patients from American Indian/Alaskan native backgrounds, one study reported no difference in ANH use; however, another study reported a slight increase of 1.17 times.

Connolly *et al.* (2012) also reported data on the mix of ethnicities in nursing homes which also influenced the use of ANH. They concluded that ANH was more likely to be used in nursing homes that had a high proportion of patients from ethnic minority groups. The ethnicity of doctors was also found to influence decisions in a hypothetical scenario, with African-American and Asian physicians more likely to recommend ANH than Caucasian physicians. Interactions between the physicians' race and the patients' race also seemed to influence decisions to provide ANH, as African-American physicians were more likely to recommend ANH for African-American patients than for Caucasian patients. This effect remained even when physician speciality and practice city size were controlled for. No difference was reported for Caucasian and Asian physicians in their decisions about ANH for African-American and Caucasian patients.

So higher rates of artificial nutrition were found in individuals with dementia or severe cognitive impairment in ethnic minority groups when compared to Caucasian groups (Connolly *et al.*, 2012). However, it is difficult to draw conclusions about why these differences were found, as there is little qualitative research in this area.

The quality of these reviews was good overall. PRISMA guidelines were followed in most reviews (Connolly *et al.*, 2012; Alagiakrishnan *et al.*, 2013; Jaafar *et al.*, 2015), which provide guidance on clear reporting of systematic reviews (Moher *et al.*, 2009). All the studies reported clear

search strategies, some of which were highly comprehensive using expansive search terms and a range of databases, some of which included locating grey literature (Connolly *et al.*, 2012). Most studies included an assessment of the quality of the studies they included (Connolly *et al.*, 2012; Alagiakrishnan *et al.*, 2013; Jaafar *et al.*, 2015; Ribeiro Salomon and Carvalho Garbi Novaes, 2015). The review by Brooke and Ojo (2015) was the poorest quality, as they did not follow PRISMA guidelines, or report any assessment of the quality of the included studies. They also used the search term 'nasogastric tube' but then excluded these studies with no explanation (Brooke and Ojo, 2015:2459). However, while this review was of poorer quality, their conclusions were comparable with the other higher quality reviews.

Conclusions from systematic reviews

These reviews show that nutritional problems are likely to occur in patients with dementia due to swallowing problems, although ANH may not be indicated due to the risk of harm. These findings are supported by guidance on the use of ANH in advanced dementia (American Geriatrics Society Ethics Committee and Clinical Practice and Models of Care Committee, 2014; Volkert *et al.*, 2015). However, patients with dementia do receive ANH, and the ethnicity of the patient and the physician caring for the patient appears to influence this. It is not clear why this might be, but suggests that decisions about ANH are influenced by multiple factors.

3.4.3 Experiences of decision-making by healthcare professionals about ANH in advanced dementia

Three main areas of original research which broadly related to experiences of decision-making by healthcare professionals about ANH, including patients with dementia, were identified. There were two systematic review articles, surveys of healthcare professionals' views, and qualitative research of different aspects of decision-making, for example roles of healthcare professionals in decision-making. These will be reviewed and conclusions drawn with reference to my research.

3.4.3.1 Systematic reviews

Two systematic reviews were retrieved from my search of the empirical literature. The first systematic review by Bryon *et al.* (2008) reviewed nurses' attitudes to ANH in patients with dementia from 14 studies. The qualitative and quantitative studies took place in six different countries and included nurses who worked in a range of settings. Their review indicated that some nurses favoured the provision of ANH and others did not. For those nurses supporting the use of ANH in patients with dementia, the arguments used to support their views included the sanctity of life, ANH being basic care, quality of life, and wanting to enable a dignified death. Cost, quality of life, and wanting to enable a dignified death were included in the arguments for those not supporting the use of ANH in patients with dementia. It is interesting to note that both sides used quality of life and a dignified death to support their own viewpoint. The authors noted that some nurses' knowledge was not up-to-date, so they were not basing their argument on current best evidence. The authors also noted that nurses'

attitudes could be influenced by doctors' orders and the expectations of family and colleagues. It was also interesting to note that the nurses who were in favour of ANH in dementia were statistically significantly more religious than those not in favour ($p < 0.04$).

The second systematic review by Clarke *et al.* (2013) did not solely focus on patients with dementia. However, their review did explore how treatment decisions about ANH were made for patients who lack capacity, so this cohort would include patients with dementia. The review included 66 studies from 40 different countries. The review identified that weight loss and a decrease in oral intake were the triggers that prompted a decision about feeding options to be made. The main factors which influenced decisions were quality of life, prolonging life, patient's wishes where they were known, and families' views. The authors reported that doctors and nurses felt conflicted about their roles with feeding. For example, some doctors recommended ANH for patients when they would not have wanted it for themselves or their family, and some nurses felt frustrated by a lack of influence on decisions.

Both these reviews contribute to the evidence base of understanding the experiences of decision-making about ANH. Both are comprehensive reviews without language restrictions on the search. Both included quantitative and qualitative studies to draw on a range of data in order to answer their clinically focused research questions. Both adopted the use of a narrative approach to presenting their findings; an explanation of why quantitative data was not combined in a meta-analysis was not provided.

The quality of the included studies was assessed, but there does not seem to be any threshold measure of quality to be included in the reviews. Bryon *et al.* (2008) included literature from America, UK, Israel, Italy, Japan, and the Netherlands. Clarke *et al.* (2013) included articles from 40 different countries including New Zealand, Sweden, Ireland, Italy, Hong Kong, Canada, UK, Israel, the Netherlands, Australia, Belgium, USA, Japan, and one study of 32 European countries, namely Austria, Belgium, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Italy, Lithuania, Luxembourg, Moldavia, the Netherlands, Norway, Poland, Portugal, Romania, Russia, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland, Turkey, UK, the former Yugoslav Republic of Macedonia.

These reviews suggest that there are varying influences on decisions in favour or against the provision of ANH for people with dementia. Quality of life was a common influencing factor for decision-making. There was some conflict experienced by doctors and nurses.

These reviews do not elucidate the experience of dietitians, again indicating a gap in existing knowledge. However, these reviews do highlight issues which may also have relevance for dietitians' experiences; for example, the influence of other healthcare professionals and family on decision-making, issues of quality of life, and the conflict experienced during decision-making.

3.4.3.2 Survey research

My search for literature related to experiences, attitudes, beliefs, or knowledge of ANH in patients with dementia retrieved 16 studies using survey methodology. These studies reported findings from different professional groups; that is, dietitians, speech and language therapists, nurses, doctors, and social workers. The key findings from these studies were that knowledge was an issue for some suggesting that their views were not informed by current best evidence. Influences on decision-making commonly included perceived of quality of life, the family's view, and additionally, for nurses, the views of other healthcare professionals. The level of perceived influence that healthcare professionals had was associated with experience and the level of involvement in the decision-making process.

Survey research - Views of social workers and speech and language therapists

Lacey (2005) surveyed American nursing home social workers about their perceptions of who had the greatest influence on various decisions about the care of nursing home residents with advanced dementia. Data about decisions regarding ANH in this group of patients is reported here. The social workers believed that medical directors had the greatest influence on medical decisions in the nursing home, followed by the director of nursing and then administrators. The social workers also reported that they believed that 43% of the medical directors took a position to discourage the use of ANH in dementia, but 30% encouraged its use if patient wishes were not clear. The social workers reported that they

believed that 29% of nursing directors and 7% of administrators took a position to discourage ANH use, but 26% of nursing directors and 64% of administrators encouraged the use of ANH in dementia. The sample size was likely to be adequate at 138. The questionnaire was developed through focus groups with nursing home social workers and reviewed by social work academics and professionals. The response rate was 'just under 50%' (Lacey, 2005:215). Although this suggests that there was a difference in positions taken by different professional groups, and that positions are not being informed by the best available evidence of benefits and harms of ANH, the major drawback of this research was that they asked the social workers to speculate about the views of other professional groups.

Speech and language therapists are often involved in the assessment of patients with dementia that have swallowing problems, and can make recommendations for non-oral feeding when there is an aspiration risk. Like dietitians, speech and language therapists make recommendations to the medical team which may or may not be followed. The search strategy revealed two studies which surveyed the views of speech and language therapists; Vitale *et al.* (2011) and Sharp and Shega (2009). These two surveys reported similar findings: that there was a lack of knowledge of the evidence base of the benefits and harms associated with ANH in patients with dementia and dysphagia.

Vitale *et al.* (2011) surveyed 712 American speech and language therapists to assess their knowledge and recommendations regarding ANH for patients with advanced dementia. They reported that 74% of the respondents felt well prepared to manage dysphagia in stroke patients, but only 42.9% felt prepared to manage dysphagia in dementia. Also, 59% of respondents indicated that within the last two years, doctors had asked them to determine whether a patient with dementia required a feeding tube.

Of those surveyed, 55% would recommend non-oral feeding if a patient with advanced dementia had dysphagia. Only 22.2% of speech and language therapists correctly reported that ANH would not reduce the risk of aspiration. However, 50.2% understood that ANH would not prevent an uncomfortable death, 54.2% understood it may not improve function, and 63.2% understood it may not enhance quality of life. This suggests that there were some knowledge gaps in the respondents.

The other survey of speech and language therapists was Sharp and Shega's (2009) survey, which aimed to describe the beliefs and practices of American speech and language therapists regarding the use of PEG in advanced dementia. For a given case scenario, most (56%) would recommend the insertion of a PEG for the provision of ANH, and 34% believed that the use of a PEG was standard care for patients with advanced dementia with dysphagia. Influences on the speech and language therapists' recommendations included those from the family (reported by 74%), primary care physician (65%), referring doctor (62%)

and dietitian (51%). The results suggest some gaps in the speech and language therapists' knowledge about the benefits of ANH.

The response rates of both studies was fair at 53.7% for Vitale and 57% for Sharp and Shega, although the risk of non-responder bias remains. For both surveys no data was collected about religion, a known influencer of decisions about ANH. In fact, Sharp and Shega used a questionnaire from a previous study (Shega *et al.*, 2003) which did ask about religion, but no data was included in the report about religion, so it was assumed that this question was omitted in the speech and language therapist questionnaire.

While the findings broaden the evidence base and introduce other healthcare professionals' views, and the results suggest issues with evidence-based practice, confidence, and influences of others on decisions, the use of surveys does not explore the real experience of the clinical practitioners in these difficult situations, which my study aimed to do.

Survey research - Doctors and nurses

Doctors have been surveyed about ANH and dementia by a number of researchers to obtain information about their knowledge (Shega *et al.*, 2003; Vitale *et al.*, 2006; Nakanishi and Hattori, 2014), attitudes (Von Preyss-Friedman *et al.*, 1992; Hodges *et al.*, 1994; Shega *et al.*, 2003), and to explore characteristics which might influence decisions (Clarfield *et al.*, 2006; Vitale *et al.*, 2006; Modi *et al.*, 2007; van Wigcheren *et al.*, 2007).

A mixed sample of doctors and nurses were also surveyed by Rurup *et al.* (2006) and Valentini *et al.* (2014), both of which explored end-of-life decisions about ANH in dementia.

Survey research - Doctors and nurses - Knowledge

The knowledge of many of the physicians surveyed by Shega *et al.* (2003), Vitale *et al.* (2006), and the doctors and nurses surveyed by Nakanishi and Hattori (2014) appeared to be inaccurate, and suggests that the sampled doctors and nurses may have believed that ANH would be of benefit in end-stage dementia. Shega *et al.* (2003) surveyed American doctors with the aim of understanding decisions to refer for PEG insertion in advanced dementia. The results suggest that knowledge about PEG was inaccurate for many of the respondents, as 76.4% (149/195) thought PEG would reduce the risk of aspiration, 61.4% thought that PEG would improve survival, and 27.1% believed that it would improve functional status. Vitale *et al.* (2006) surveyed primary care physicians in America. Indications for ANH in dementia were reported as recurrent aspiration pneumonia by 64.2% (412/642) of respondents, aspiration risk following bedside assessment by 57.8%, and 52.4% following videofluoroscopy indication aspiration. The authors concluded that physicians' misconceptions about indications for ANH predominated in their sample of respondents and that they may believe that ANH was of benefit in end-stage dementia. Japanese nurses and doctors were surveyed in hospitals and long-term care homes about the patients they cared for with advanced dementia who had a PEG for ANH by Nakanishi and Hattori (2014). The

majority (51.1%) of the nurses and doctors who were questioned about 3359 patients receiving ANH via a PEG believed that the PEG would prolong survival. Of those questioned, 39% expected the PEG to improve their patients' quality of life.

Survey research - Doctors and nurses - Attitudes and influences

Surveys conducted by Von Preyss-Friedman *et al.* (1992), Hodges *et al.* (1994), and Shega *et al.* (2003) shed light on the attitudes and influences of other healthcare professionals on decisions by doctors about ANH in dementia.

Von Preyss-Friedman *et al.* (1992) explored doctors' attitudes to providing ANH to chronically ill nursing home patients. They used 16 different case scenarios, which included some patients with dementia. They surveyed randomly selected doctors from the American Geriatric Society and the American Medical Association. The response rate was 41% (n=141), with a greater response rate from the American Geriatric Society members of 53%, compared to 29% for the American Medical Association. The results suggested that while cognitive status did influence decisions to start feeding ($p < 0.02$), the greatest influences were patient preference (expressed when they had capacity), family preference, and life expectancy ($p < 0.001$). Cognitive status had a greater influence on decisions to withdraw ANH ($p < 0.001$) compared to decisions to start ANH.

The views of Italian nurses and doctors about providing ANH in end-stage dementia has been reported by Valentini *et al.* (2014). They surveyed 288 doctors and 762 nurses via the use of a questionnaire to obtain their opinions about the use of ANH in advanced dementia. Of the completed sample of doctors and nurses, 47% agreed that ANH should be provided to terminal patients with dementia. The authors suggest that this means only 1 in 4 followed the guidance on ANH not to be administered to such patients.

Hodges *et al.* (1994) conducted a survey of American doctors to explore whether they would provide ANH to a patient with advanced dementia as described in a case vignette. Of those surveyed, 84% would not feed a patient with advanced dementia and 84% (488/581) of doctors believed ANH to be a medical therapy. However, 16% believed it to be basic humane care. Of those who would feed a patient with advanced dementia, 44% believed that it was a doctor's role to sustain life, 33% believed that ANH reduced suffering, and 10% believed that all patients should be fed. The authors concluded that prognosis was the main influencing factor for the doctors' decisions.

Similar findings were reported by Rurup *et al.* (2006) who explored the attitudes of 107 doctors and 148 nurses towards end-of-life decisions in patients with dementia in nursing homes in the Netherlands. The questionnaires were completed on the day a decision was made to start or forego ANH. For some aspects there was a lot of agreement between

doctors and nurses. For example, 60% of doctors and 62% of nurses agreed that when a patient refuses to eat and drink it should be respected. Also, 92% of nurses and 95% of doctors disagreed that withdrawing ANH was negligent. However, views differed on whether foregoing ANH was followed by a peaceful death. Of the doctors who responded, 89% believed that death was peaceful, but only 57% of nurses agreed that death was peaceful. The authors suggested that this might be because the nurses are more involved in caring for the patient during the dying process, or because the nurses' perceptions of a peaceful death are different to the doctors. However, it does give an indication of differing experiences that doctors and nurses might have.

An indication of some of the emotion associated with decision-making was captured by Valentini *et al.* (2014). They reported that compared to doctors, the nurses appeared to express more emotion; nurses reported a greater level of sadness than the doctors, and agreed more often than the doctors that life should be respected, but that there is a right to die.

Survey research - Doctors and nurses - Characteristics and other factors

The results of a number of surveys give an insight into various characteristics and other factors which might influence decisions about the use of ANH in people with dementia (Shega *et al.*, 2003; Clarfield *et al.*, 2006; Vitale *et al.*, 2006; Modi *et al.*, 2007; van Wigcheren *et al.*, 2007). The ethnicity of the doctor was one of a few factors noted as being associated with recommendations for PEG in a survey of American

doctors (n=1083) using case vignettes by Modi *et al.* (2007). The greatest proportion of recommendations for PEG placement was by Asian doctors (54.3%) compared to African-American doctors (40%) and Caucasian doctors (13%). The analysis also noted an association between recommendations by African-American doctors and the ethnicity of their patient vignette. These doctors were more likely to recommend PEG feeding for African-American patients with dementia than for Caucasian patients ($p=0.029$, OR 3.84, no CI provided). The doctor's speciality and the number of patients the doctor had cared for with PEG were associated with the doctor's recommendation for a PEG. Family medicine doctors were more likely to recommend PEG compared to internal medicine doctors or those working in care of the elderly ($p<0.001$). If doctors had cared for more than 10 patients with a PEG they were also more likely to recommend PEG ($p<0.024$).

Speciality, experience, and working environment also seemed to be important characteristics of American primary care doctors in a survey by Vitale *et al.* (2006). Doctors with experience of working in nursing homes and with experience of caring for patients with a PEG had a greater knowledge of the indications for PEG compared to those without those experiences. Experience also appeared to be a factor in the survey by Rurup *et al.* (2006) of nurses from nursing homes in the Netherlands. Compared to less experienced nurses, nurses with more experience were more likely to agree that refusal to eat or drink should be respected, and that foregoing ANH was almost always followed by a peaceful death. The

authors do not speculate as to why this might be: could it be because the more experienced staff have become blasé about death and dying? Similarly, the doctors and nurses that worked in care of the elderly or had training in palliative care in the survey reported by Valentini *et al.* (2014) were less likely to agree to the administration of ANH. The reports from the survey by Teno *et al.* (2014) also indicate that speciality is important, with the type of attending doctors influencing the decisions made. When American nursing home patients with advanced dementia were admitted to hospital with dehydration or infection, decisions to insert a PEG varied from just 1.6% to 15.6% depending on the speciality of the attending doctor.

In a related but slightly different survey, Teno *et al.* (2010) considered the characteristics of the American hospitals that nursing home patients with advanced dementia were admitted to and whether this influenced decisions regarding the provision of ANH. The rates of tube insertion did vary between hospital type, (0 to 38.9 per 100 hospitalisations) and rates were higher in for-profit hospitals, larger size hospitals, and those where there was a greater use of ICU in the last six months of life.

Van Wigcheren *et al.* (2007) reported team decision-making about the use of ANH in nursing homes in the Netherlands via a survey to nursing home physicians (n=704). They found that nurses had little influence on doctors' decision-making, with just 2% of doctors citing wishes of the nurse as an influencing factor, although the doctors reported that nurses were

participants in the decision-making process 85% of the time. The patient's overall condition, followed by the presumed wishes of the patient and then family wishes had the greatest influence on decision-making. As nurses were not included in the sample it is not possible to verify if the nurses agreed that they were involved in the decision-making process, and there is the risk of recall bias when asking about previous cases.

Religion has been shown to influence doctors' and nurses' decisions about treatment (Curlin *et al.*, 2007a; Curlin *et al.*, 2007b; Curlin *et al.*, 2008; Lawrence and Curlin, 2009; Seale, 2010; Body, 2011; Chung *et al.*, 2012; Wolenberg *et al.*, 2013), and this influence appears to remain for patients with dementia. Of the American doctors who responded to the survey by Shega *et al.* (2003) 27% thought that their own religious beliefs influenced their decision-making. Similar findings were reported in the survey by Rurup *et al.* (2006) of doctors and nurses who work in nursing homes in the Netherlands with patients with dementia. Of those who reported to have a faith, 28% and 21% of doctors and nurses respectively reported that their religious beliefs did influence ANH decision-making, while 17% of doctors and 36% of nurses reported that their religious beliefs did not influence decisions about ANH. Of course, subjects may not be aware of subtle influences of their own values on their thinking. A much higher rate was reported by Valentini *et al.* (2014), where 65% of the total sample of Italian nurses and doctors believed that their own religion was important for end-of-life decisions. This compares to 23% of Canadian dietitians previously noted in the survey by Taper and Hockin (1996).

The cross-sectional survey by Clarfield *et al.* (2006) compared differences in practice when providing ANH to patients with end-stage dementia in Canada and Israel. More patients received ANH in Israel (52.9%), followed by Jewish affiliated hospitals in Canada (19.6%), followed by non-Jewish Canadian patients (4.7%), $p < 0.001$. This appeared to be related to being Jewish, with Jewish patients receiving ANH more often than Christian patients, although country (being in Israel) also influenced the practice. Israeli Jews had highest rates of feeding at 51.7%, followed by Canadian Jews at 18.9%, and finally, Christians at 3.2% ($p < 0.001$). The authors suggested that the difference might be as a result of administrative and financial reasons as well as culture and religion.

External pressures was one of the associations reported by Shega *et al.* (2003) in their survey of American doctors with the aim of understanding decisions to refer for PEG insertion in advanced dementia. Doctors reported pressure from others which influenced their referral for PEG insertion, with 66% reporting pressure from speech and language therapists, 64% from nurses, 95% from family, and 67% from the nutrition team (there was no specific mention of a dietitian). Given these external pressures, it was not surprising that 41.6% reported that they ordered a PEG even though they thought it was not the best course of action, and 10% reported that they had acted against their conscience by withholding PEG. Family pressures to provide ANH was also noted in a survey of American doctors conducted by Von Preyss-Friedman *et al.* (1992). When patient preference and family wishes agreed, doctors were more likely to

concur with that decision. However, when there was not agreement, the doctors were less likely to agree with the patient wishes, suggesting that family pressure did influence the doctors' decision-making.

Survey research - Studies with only nurses

Finally, in this survey section, surveys which just sampled nurses will be considered. Two surveys were retrieved from the literature search which only surveyed nurses. Lubart (2004) surveyed head nurses in Israel who had been involved in the care of patients with dementia who had been receiving ANH for at least a year, and Ryan and McNamara (2001) surveyed Irish nurses about ANH in advanced dementia. The 111 surveyed nurses in Lubart's (2004) survey expressed ambivalence; most believed that ANH was essential life support, but most also expressed that ANH might prolong suffering. However, only 10% would support withdrawing ANH.

In the survey by Ryan and McNamara (2001), 57% of the nurses who responded did not feel involved in the decision-making process to begin ANH. Their findings also suggested a lack of knowledge, with 58% believing ANH could prevent aspiration pneumonia, reduce pressure ulcers, reduce the consequences of malnutrition, would improve survival rates, and reduce the risk of infection. The authors stated that surveyed nurses were influenced by family views, (59% had experience of opposition from family members about starting ANH with their family member) and that 84% supported the use of advance directives to help

with decision-making. While these findings from Ryan and McNamara (2001) are interesting, it is likely that religion will have had an influence.

It was head nurses who completed the survey by Lubart (2004), so the views of junior nurses, or those more clinically involved with patients, may differ. The authors did not give an indication of response rates, which is of concern as it is not clear how representative the findings are of other nurses in this population, and whether there was a risk of responder bias.

Ryan and McNamara (2001) do state response rates of 70%, but this was a report of a conference proceeding, therefore the full text was not available. This, together with the fact that some characteristics were missing (such as demographic data for the nurses), makes it difficult to assess the quality of this research.

Quality of the reviewed surveys.

Some of these surveys were affected by poor response rates, suggesting possible non-response bias; the Vitale *et al.* study (2006) had a response rate of just 8.6% even after extensive attempts to improve it. Many surveys used vignettes, some multiple vignettes, (for example, Von Preyss-Friedman *et al.* (1992)), although these may not be reflective of real practice. Hodges *et al.* (1994) and Nakanishi and Hattori (2014) tried to deal with this limitation by just using survey results from doctors and nurses with personal experience of caring for patients receiving ANH. Other researchers extracted data from medical notes (for example,

Clarfield *et al.* (2006)), while others asked about actual real clinical decisions which had been made (for example, van Wigcheren *et al.* (2007) and Rurup *et al.* (2006)). While this removes the limitations of using vignettes, there is still the risk of recall bias when asking about previous cases.

Some surveys did have excellent response rates; Rurup *et al.* (2006) reported 96% and 94% for doctors and nurses respectively, and van Wigcheren *et al.* (2007) reported a response rate of 77%. However, the latter survey's respondent sample was not representative of the general nursing home physician population in terms of gender or age.

The survey by Modi *et al.* (2007) had a response rate of 47.7% (981 questionnaires), which is reasonable and was ethnically representative of the population it was sampled from. They undertook subgroup analysis to look for associations between ethnicity and decisions. The majority of the doctors questioned (85.5%) were Caucasian, and just 6.1% of the sample of 981 (that is, 60 doctors) were African-American; therefore the absolute numbers of African-American doctors was small, so it is not clear if these findings would be similar in a larger sample of African-American doctors.

While some researchers report collecting information about religion, not all studies reported this information, for example, Hodges *et al.* (1994), which is important as religion is known to influence decisions about ANH.

Summary and implications of survey research

A strength of this survey research is that the views of a range of different healthcare professionals have been obtained. There are a number of key findings relevant to this study.

There were gaps in knowledge and evidence-based practice by doctors, nurses, and speech and language therapists. Decisions were influenced not only by patient factors such as prognosis and patient preferences, and by family preferences or views, but also by other healthcare professionals. Some doctors felt so pressured to make a certain decision that they made recommendations for PEG which they did not agree with, or acted against their conscience to withhold PEG, suggesting an emotional cost and possible moral distress. Other influences included religion, clinical experiences or speciality, and the working environment. Finally, some nurses did not feel adequately involved in the decision-making process.

Gaps in the knowledge of healthcare professionals have implications for shared decision-making. Accurate information should be provided to patients in order for them to consider their options, and if the healthcare professionals' knowledge and evidence base is lacking, this cannot adequately occur. Within teams these gaps in knowledge may affect decision-making and team working. It could lead to conflict within teams if those in positions of power do not have an adequate knowledge base. Conflict may also be an issue if those who believe they should be involved in decision-making are not.

While these surveys have interesting findings, there are limitations as previously discussed. Many of the surveys were conducted in the USA where the health system is different, where there may be financial pressures, and where there may be different medico-legal influences compared to the UK. They often report associations, which can lead to over simplification of the clinical situation, and do not give in-depth detail about the experience or capture emotional experiences which have been hinted at in some surveys. For these factors to be explored, a qualitative research approach is required.

3.4.3.3 Qualitative research

Introduction

While survey research can help to set the scene and can give an indication of the proportion of people who report thinking and acting in a particular way, it often does not explore the real life experience of clinical practice. Survey research is not able to elucidate the experience of healthcare professionals. Qualitative research can capture the complexity of decision-making and the emotional components which were previously alluded to. Therefore, I will now explore qualitative research.

The literature search I conducted retrieved 11 qualitative research articles related to the experiences of decision-making about ANH in dementia. These included experiences from doctors and nurses and healthcare assistants. Many of the aspects reported in the qualitative research were

related to the complexity of the decision being made (Wilmot *et al.*, 2002) and the conflict and uncertainty involved (Norberg *et al.*, 1987; Wilmot *et al.*, 2002). A large number of studies reported the ethical principles drawn upon during decision-making (Bexell *et al.*, 1980; Norberg *et al.*, 1987; Norberg *et al.*, 1994; Day *et al.*, 1995; Wilmot *et al.*, 2002). The role of doctors and nurses in decision-making has also been reported (The *et al.*, 2002; Bryon *et al.*, 2010; Lopez *et al.*, 2010a; Bryon *et al.*, 2012). Some studies reported the emotional aspects and influences on decision-making (Pasman *et al.*, 2004; Aita *et al.*, 2007; Buiting *et al.*, 2011; Bryon *et al.*, 2012).

The complexity of decision-making

The complexity of making decisions about ANH in advanced dementia was explored by both Wilmot (2002) and Norberg *et al.* (1987). Wilmot *et al.* (2002) used focus groups with UK NHS nurses, and Norberg *et al.* (1987) used one-to-one interviews with different grades of Swedish nurses. Wilmot (2002) concluded that the nurses experienced conflicts in decision-making related to three areas: well-being, autonomy, and preserving life. For example, not using ANH might mean that patients choke on their oral diet, but removing food might mean removing a source of enjoyment for the patient. They also reported conflicts around respecting patients' autonomy if they refused to eat, as not providing ANH might mean that a patient starves. However, many nurses felt that life should be preserved.

Norberg *et al.* (1987) explored the uncertainty some nurses felt in relation to suffering; would suffering be increased or decreased by not providing ANH? They also felt conflicted between professional demands and personal views, suggesting some moral distress. It is important to note that not all nurses reported feelings of conflict. Some were very certain in their view that ANH should or should not be provided.

The ethical principles used during decision-making

The ethical principles used during decision-making about ANH in dementia have been illuminated by a number of studies (Bexell *et al.*, 1980; Norberg *et al.*, 1994; Day *et al.*, 1995; Wilmot *et al.*, 2002). The participants in these studies drew upon varied ethical principles depending on their viewpoint; they appeared to use the ethical principle which fitted with their viewpoint. Day *et al.* (1995) interviewed American nurses using a vignette of a patient with dementia who refused to eat. The nurses who were against feeding used the principles of autonomy and quality of life to guide their views; those for feeding were guided by beneficence and sanctity of life. Norberg *et al.* (1994) interviewed nurses from America, Australia, Canada, China, Finland, Israel, and Sweden. The principle of sanctity of life was cited by nurses who were for the provision of ANH in severe dementia. Autonomy was the principle cited by nurses who were against using ANH in severe dementia. All nurses valued the principle of beneficence. Chinese nurses referred to their love of people in the justification for feeding. Similar findings were found by Bexell *et al.* (1980) who used focus groups with Swedish nurses to explore the difficult

decision to feed or not in advanced dementia. Nurses ranked sanctity of life highly if they were for feeding. However, if they ranked quality of life highly, they were against feeding. UK nurses also appear to follow this trend. Wilmot *et al.*'s (2002) focus groups of UK nurses revealed that the nurses' view of the difficulties associated with feeding in dementia was underpinned by the principles of autonomy, quality of life, and sanctity of life, which they used to support their viewpoint.

Roles and relationships in decision-making

Survey data indicates that nurses would like to be more involved in decision-making, but that they have little actual influence on the decision made. To expand this further, the roles and relationships that nurses and doctors undertake in decision-making about ANH in dementia have been explored in a number of qualitative studies.

An ethnographic study conducted by Pasman *et al.* (2004) observed healthcare professionals and patients' relatives in two Dutch nursing homes in order to determine the role and influence of these groups on decision-making about ANH. Of the nurses, doctors, and relatives observed, the doctors had the biggest influence on decision-making. Some doctors encouraged open discussion from all, and nurses felt involved in decision-making, while other doctors did not promote open shared decision-making. However, there was an overall feeling of good team working between the doctors and nurses.

Similar findings were reported in an ethnographic study conducted in nursing homes in the Netherlands by The *et al.* (2002), which aimed to clarify the practice of withholding ANH from patients with dementia in nursing homes. Data was collected from two nursing homes via observation and interviews. Doctors made the decisions about ANH, but they experienced uncertainty related to a lack of clarity about patients' wishes, and about possible changes in patients' clinical conditions. Doctors coped with this by including others, especially family members, in the decision-making process. Nurses' opinions were sought and the nurses aimed to influence the doctors by questioning their decisions. The authors do not note any emotional impact on the doctors of these experiences.

The American nurses interviewed in a study conducted by Lopez *et al.* (2010a) took more of a passive role in decision-making compared to the previous research. Lopez *et al.* (2010a) investigated nurses' roles in feeding decisions for patients with advanced dementia who were cared for in nursing homes. Nurses had a role in identifying weight loss and communicating this to other healthcare professionals. They also had a role in facilitating communication between doctors and the family members during discussions about ANH. Interestingly, many of the nurses believed that they needed to take a neutral role in these decisions; they were fearful of expressing their own view. This led to a lack of involvement by them in discussions with doctors and family, other than to state factual information, for example, the feeding difficulties that patients were experiencing. Many

nurses were aware of some of the moral issues associated with providing ANH in advanced dementia, but they compartmentalised these into a personal view, so as not to influence their professional practice. The authors suggested that this resulted in nurses who were not actively involved in team decision-making, who did not recognise the moral elements to their practice, and so did not support families during these decisions. The authors suggest that this might be because of a lack of knowledge about end-of-life decision-making and confusion about their role within the decision-making process. They suggested that education was key.

So while some of the American nursing home nurses (Lopez *et al.*, 2010a) did not want to be actively involved in decisions, many of the nurses in the series of studies by Bryon *et al.* (2010; 2012a; 2012b) did want to be involved in decisions, as they believed that they knew the patient and believed that they knew what was the best decision for them.

The first of the series of Bryon *et al.*'s (2010) qualitative studies aimed to explore in what ways and to what extent Belgian nurses were involved in decisions for hospitalised patients with dementia to have ANH. The authors conducted 21 one-to-one interviews with nurses. The overall findings were that nurses strived to provide the best care for their patients. The nurses believed that they knew their patients, therefore had a holistic picture of what their patients needed. Good care was enabled by getting to know their patient and by good communication with family and the patient.

When doctors made the final decision about whether to provide ANH, it was viewed through the nurses' lens of what 'good care' was for that patient. If the nurse agreed with the decision, they complied with it. If they did not agree, some resisted the decision either openly or covertly. Some nurses tried to change the decision, while others were passive. The key roles that the nurses believed they had in the decision-making process were to highlight that nutrition had become a problem; they acted as patient advocates by virtue of believing that they knew the patient; and they provided information to the patient's family, often by acting as intermediaries between the doctor and the family. Some nurses reported having conflicting roles between acting as patient advocate and being empathetic to the family who wanted everything possible to be done for their family member. During the actual decision-making process, nurses that were seen as part of the team and recognised for their expertise were involved in the decision. However, nurses who felt that they worked in a hierarchical environment believed that there was little consultation with nurses, resulting in the nurses feeling that they were not being heard and were spectators implementing doctors' decisions.

The influence of Belgian nurses on doctors' decisions was investigated by Bryon *et al.* (2012a) in a study which aimed to explore nurses' experiences of communication with doctors about ANH decisions for patients with dementia. They interviewed nurses about the different ways they influenced doctors' decision-making to achieve what they believed to be best possible care. These experiences could be positive or negative,

depending on how much the nurses felt that they influenced the doctors to achieve 'best care'. Negative experiences were related to having little involvement in decisions, feeling that they were just enacting doctors' decisions and feeling insecure, inferior, and intimidated by doctors. This led to a feeling of distress and powerlessness. Positive experiences were related to nurses feeling involved in the decision-making, feeling that they were valued, respected and listened to.

Qualitative research by Buiting *et al.* (2011) reported 31 Dutch and Australian doctors' decisions about ANH in advanced dementia. Overall, the doctors were too reluctant to start ANH and used similar medical considerations in their decision-making. However, it appeared that the Dutch and Australian doctors used different approaches to come to their decisions. Dutch doctors had longer relationships with their patients and family, which facilitated them to be more proactive in decision-making; the authors also report that they took more responsibility for decision-making than the Australian doctors they interviewed. The Dutch doctors focused more on the patients' current situation, whereas the Australian doctors considered research evidence and advance directives during their decision-making. They were also more likely to leave the decision to relatives.

Emotions in decision-making

As decision-making about ANH is often complex and difficult, it is not surprising that many studies have revealed an emotional dimension in their findings. The studies by Pasman (2004), The (2002) and Bryon *et al.*

(2010; 2012b) suggest that this is important because emotions can influence the decisions made and can have an impact on the healthcare professional involved.

The findings of an observation study by Pasman *et al.* (2004) included the symbolic and emotional responses to ANH. They observed that some doctors continued ANH at low levels for 'symbolic value' rather than 'therapeutic value' as they thought it would help the family. They also noted that nurses often had an emotional involvement with the patients; they were affected by the patients' clinical condition and the nurses believed that they had to stand up for the patient. When doctors perceived this, they kept the nurses at a distance. The doctors involved the nurses in decision-making when they believed them to be less emotionally involved and had what they believed to be a professional, more distant attitude.

Bryon *et al.* (2010; 2012b) report the emotional experiences of one cohort of Belgian nurses caring for patients with dementia in a nursing home in two papers. In the first paper the nurses felt that they were not being listened to, did not agree with the decisions made, and described emotions of 'disbelief, indignation, frustration, anger and disgust' (Bryon *et al.*, 2010:1111). When relatives asked the nurses about decisions the nurses did not agree with, they did not question the doctor's decision in front of the family, suggesting some emotional labour (the moderation of the outward display of emotions) was being undertaken. There also appeared to be some moral distress in this cohort of nurses, as they

implemented the doctor's decision because of the doctor's power, even though the act was against their conscience. The Bryon *et al.* (2012b) study explored how the nurses were touched by the vulnerability of their patients. Care was described as being 'emotionally taxing' as the nurses connected with their patients personally as well as professionally (Bryon *et al.*, 2012:289). When nurses were involved in decision-making they had great satisfaction with the decision made, and when they were not involved they described feeling powerless and angry. The nurses found it emotionally difficult to see their patients dependent on others, defenceless and fragile, which led to some nurses feeling guilty about the treatment some patients received. To cope with these emotionally difficult situations, some nurses learnt to distance themselves.

While the Dutch and Australian doctors in the qualitative research by Buiting *et al.* (2011) came to the same decisions, there were emotional differences between the two groups. The Dutch doctors reported having more emotional difficulties with withdrawing ANH. The authors suggest that this was due to the relationships the doctors had with their patients and the family. However, the Australian doctors interviewed did not report relationships with their patients or the family, and did not experience an emotional difference between withdrawing and withholding ANH in their patients with advanced dementia.

Culture

As previously described, survey data suggests that culture can influence decision-making about ANH in dementia. Some of the qualitative research retrieved from the literature search explored this further. Aita *et al.* (2007) described physicians' attitudes in Japan, and Lopez *et al.* (2010b) compared two different nursing homes' decisions about ANH. Aita *et al.* (2007) suggest that the provision of ANH to people with severe cognitive impairment through a PEG was standard practice in Japan. These authors interviewed 30 physicians about factors which influenced their decisions to provide or withdraw ANH. The medico-legal systems in Japan were a major influence on decisions to provide ANH. Many participants were of the view that ANH was being provided for the family's benefit rather than for the patient's. Participants believed that Japanese culture was different to the 'West' in that life is lived to fulfil others' happiness, not one's own. Therefore, if it was a family's wish to prolong life through ANH, it was provided.

The culture of an institution appeared to influence the use of ANH in advanced dementia in the American study by Lopez *et al.* (2010b). They reported that a 'home-like' culture which encouraged meal times and hand feeding had a lower rate of tube feeding when compared to a more institutional-style setting. Within the decision-making process, the low ANH-use nursing home had a greater team approach, better communication with the family, and was doctor led. In the nursing home with high ANH use, the nurses informed families of feeding problems and

there appeared to be less team decision-making. Decisions to place tubes were often made in hospital when patients were admitted with dehydration (Lopez *et al.*, 2010b). Lacey's (2005) study with American nursing home social workers makes a similar observation that decisions to provide ANH to people with advanced dementia were more likely to be taken by medical or administrative decision makers. These decisions were counter to those made by palliative care experts to not provide ANH.

Quality of the research

The quality of the qualitative research is good overall, with appropriate data collection methods and in-depth observation in some ethnographic studies. Vignettes were used in some studies to prompt discussion and debate. Hughes and Huby (2002) suggest that using vignettes in qualitative research can be useful to focus discussion and it has been suggested as being less problematic than using vignettes in surveys if it aids reflection (Torke *et al.*, 2008). A range of participant voices were heard in the reports, and many studies were transparent as far as the position of the researcher. Concepts of autonomy and quality of life were considered by some authors, although the complexity of these issues in dementia are not fully explored, for example, if refusal to eat really meant that a patient with advanced dementia was expressing a desire to die.

Summary

The qualitative research reviewed above illustrates the experiences of nurses and doctors in this complex area of clinical care. It highlights that

doctors have the main influence on decision-making about the provision of ANH to patients with dementia. It suggests that conflicts can be felt by nurses and doctors, often due to the uncertainty of the consequences of a decision made, for example, whether suffering will result. Some doctors recognised the symbolic nature of ANH. While ethical principles were used, these were often selected to fit with a particular viewpoint. Not all nurses seemed to act morally, as some did not see that their role included active involvement in actual decisions about ANH. However, most nurses wanted to be involved in the decision-making process, and believed that they acted as advocates for their patients who they got to know. When this happened, the experience was positive for the nurses; they felt respected. However, when it did not happen, and the nurses did not feel listened to, they experienced distress, felt powerless, frustration, and anger.

The culture of the work environment influenced decisions. A more institutionalised environment which had hierarchical structures gave more ANH, had less team discussion, and less team decision-making compared to more home-like environments. Nurses did get emotionally involved with their patients; doctors were aware of this and excluded emotionally involved nurses from decision-making but included what the doctors perceived to be more professional unemotional nurses in the decision-making process. To protect themselves, some nurses actively distanced themselves from the emotions of the situation. Some nurses appeared to experience emotional labour and moral distress.

The literature reviewed regarding decision-making and ANH in dementia leads to questions about the professional nature of working in this area. For example, nurses reported feeling powerless and unable to influence decisions (Uden *et al.*, 1992; Oberle and Hughes, 2001; Bryon *et al.*, 2008; Bryon *et al.*, 2012a). Nurses also reported that they were unable to take on their professional role of acting as patient advocates (Bryon *et al.*, 2012a). These experiences resulted in emotional labour for some nurses (Bryon *et al.*, 2010). Research that explores dietitians' experiences in this area is likely to raise similar issues.

The nurses' experiences have the potential to affect patient care, therefore to explore this further the literature around advocacy and emotional labour will now be reviewed. I will then continue this literature review by considering some of the professional issues this literature raises.

3.5 Emotional labour

The literature about experiences of involvement of the provision of ANH to patients with dementia included descriptions of emotions and emotional labour. Management of emotions is an aspect of professionalism (Van De Camp *et al.*, 2004), therefore the concept of emotional labour and the latest research about emotional labour in healthcare will now be considered.

3.5.1 Definition of emotional labour

Hochschild (2012) first coined the phrase emotional labour in 1983 following her work with air stewardesses. She defined it as 'the

management of feeling to create a publicly observable facial and bodily display' (Hochschild, 2012:7), and that it requires the inducement or suppression of feelings 'in order to sustain the outward countenance that produces...the sense of being cared for in a convivial and safe place' (Hochschild, 2012:7). Since this seminal work there has been a wealth of research published in the area, and some revisions of this definition, including a comprehensive definition by Grandey (2000). She defined emotional labour as 'enhancing, faking or suppressing emotions to modify the emotional expression' (Grandey, 2000:95), thus it is 'the process of regulating both feelings and expressions for the organizational [sic] goals' (Grandey, 2000:97). These expressions, or display rules, dictate the emotions which should be shown in any given situation in order to match organisational goals, that is, the professional face or working persona (Hunter and Smith, 2007; Huynh *et al.*, 2008).

Emotional labour can be undertaken by the use of surface or deep acting (Schmidt and Diestel, 2014). Hochschild (2012) defined surface acting as the ability to deceive others about how we are feeling without deceiving ourselves, that is, faking it. Schmidt and Diestel (2014) note that surface acting is related to conforming to expected displays of expression dictated by an organisation. Deep acting has been defined as being able to deceive oneself and others about our true emotions by exhorting the required emotion, that is, similar to method acting (Hochschild, 2012).

3.5.2 Emotional labour in healthcare

Hochschild (2012) recognised that health service workers are likely to undertake emotional labour due to their interactions with people. Patients and carers are likely to feel emotionally vulnerable when in hospital, so will need emotional support from health professionals, which may require emotional labour on the part of the health professional (Theodosius, 2008). Indeed, empirical research, using quantitative and qualitative methodologies in a range of countries (America, Australia, Canada, Ireland, Malawi and the UK), has described and identified emotional labour in a range of health professions. For example, in nursing (Brotheridge and Grandey, 2002; Miller *et al.*, 2008; Gray, 2009; Gray, 2010; Hilliard and O'Neill, 2010; Hayward and Tuckey, 2011; Minto and Strickland, 2011; Pisaniello *et al.*, 2012; Cheng *et al.*, 2013; Sawbridge and Hewison, 2013; Msiska *et al.*, 2014), in midwifery (Hunter, 2005; John and Parsons, 2006), in medicine (Minto and Strickland, 2011; Rogers *et al.*, 2014), and in social work (Brotheridge and Grandey, 2002).

The results from the quantitative survey by Brotheridge and Grandey (2002) concluded that working in a human service role as a nurse or social worker resulted in higher levels of emotional labour via the display of positive emotions compared to the other workers (service or sales workers, managers, clerical staff, and physical labourers). Other surveys reported the negative effects of emotional labour. Pisaniello *et al.* (2012) noted that high levels of emotional labour in nurses predicted negative psychological outcomes, and that surface acting had negative effects on nurses'

perception of quality of care. Cheng *et al.* (2013) concluded that hiding emotions predicted burnout and a higher staff turnover in nurses. Within medicine Rogers *et al.* (2014) reported that surface acting was associated with work-related burnout in Australian junior doctors.

Briefly, the main themes from the qualitative research were that it was expected and recognised that nurses and midwives needed to undertake emotional labour as part of their caring role (John and Parsons, 2006; Gray, 2009; Gray, 2010; Hilliard and O'Neill, 2010; Minto and Strickland, 2011). Emotional labour was needed when there was conflict related to hierarchy between nurses and doctors (Miller *et al.*, 2008) or junior and senior midwives (Hunter, 2005). When nurses' emotional boundaries shifted, it could lead to distancing or connecting from patients and families (Hayward and Tuckey, 2011; Msiska *et al.*, 2014), which might negatively affect compassion and so have a negative effect on nursing care (Sawbridge and Hewison, 2013). It is interesting to note that in both the survey and qualitative research, the importance of support for staff was noted.

Very little has been reported about dietitians and emotional labour. Some authors have indicated that emotional labour was taught to student dietitians, as North American dietetic programmes taught students to suppress their emotions (DeVault, 1999; Gingras, 2010). Although these authors did not use the term, it does suggest emotional labour, the suppressing of emotions. Forseth's (2001) doctoral thesis on emotional

labour in interactive service work, suggested that dietetics was a profession which had a low demand for emotional labour. However, she also states that health service workers have a high demand for emotional labour. There was no discussion of this and 'dietetics' appears as just one word in a table in an appendix. This view was not explained and might be related to the perception of dietetic practice in Norway in 2000. Emotional labour had been described in dietitians working in South Korean food services (Kim, 2010; Cho *et al.*, 2011; Choi and Kim, 2012). However, these articles have only been reviewed as abstracts, as the main texts are in Korean, and it is likely that these roles have little relevance to UK clinical dietitians.

3.5.3 Empirical research about emotional labour

As suggested above, there is a wide evidence base about emotional labour. Therefore, for this literature review, I have focused on two recent reviews of the literature and recent survey research to give an overview of emotional labour within healthcare settings.

Literature reviews in emotional labour

Hülshager and Schewe (2011) conducted a systematic review and meta-analysis of quantitative research into emotional labour, well-being and performance. This included assessing the associations between well-being and how emotional labour was undertaken, that is, by surface and deep acting. The review found that when subjects experience emotional dissonance (showing emotions which are not felt) and used surface acting,

it had a negative effect on well-being and performance. However, when subjects used deep acting, it had a positive effect on performance and a smaller negative effect on well-being compared to surface acting.

This review included research from 95 studies, including 35 unpublished papers, reducing the risk of publication bias (Higgins and Green, 2011). The major limitation of this review was the search strategy, which reduced the external validity. While the authors did search eight databases, they only searched Medline and not CINHAL or EMBASE, therefore research with nurses and other health professionals may not have been retrieved. Indeed, only one study with nurses was included in the review. So while this review provides a broad overview of the effects of surface and deep acting, caution is needed when extrapolating this to healthcare staff and settings.

Riley *et al.* (2016) conducted a thematic synthesis of qualitative studies to identify the range of emotional labour undertaken and the implications for staff and healthcare organisations. They concluded that emotional labour may be required in order to undertake and demonstrate caring, and this was often viewed as 'women's work'. The suppression of emotions was evident in male-dominated professions where it was expected that emotions would be controlled and suppressed. Common sources of emotional labour were related to situations which caused distress, where there was suffering, trauma, death, bereavement, anxiety, and anger. They also reported that emotional labour was undertaken when managing

conflicts with colleagues and challenges with the organisational hierarchy, particularly when support was lacking and emotional labour was not recognised. Some healthcare professionals found emotional labour stressful and some struggled to manage their emotions. Strategies employed by healthcare professionals included emotionally distancing and desensitisation in order to cope with difficult feelings. The need for support and training and to identify and value emotional labour within clinical practice was also highlighted. This review included studies covering a range of healthcare professionals, namely nurses, midwives, medical students, paramedic students, and healthcare assistants from the UK, America, Canada, and Australia. The authors adopted a comprehensive search strategy to locate relevant research, searching six databases with comprehensive search terms. Nine studies were included, which were all appraised for quality.

Survey research into emotional labour

My search of literature relating to emotional labour revealed six surveys published in the last five years relating to healthcare (Bartram *et al.*, 2012; Chou *et al.*, 2012; Karimi *et al.*, 2014; Schmidt and Diestel, 2014; Golfenshtein and Drach-Zahavy, 2015; Tsukamoto *et al.*, 2015). These surveys were conducted with nurses from Taiwan (Chou *et al.*, 2012), nurses from Germany (Schmidt and Diestel, 2014), nurses from Australia (Bartram *et al.*, 2012; Karimi *et al.*, 2014), nurses from Israel (Golfenshtein and Drach-Zahavy, 2015), and staff who worked in Japanese long-term care centres (Tsukamoto *et al.*, 2015).

Karimi *et al.* (2014) surveyed Australian community nurses to investigate associations between emotional labour, well-being, and stress. The reported emotional labour had a significant effect on nurses' well-being and perceived job stress. They found that the more emotional labour experienced by nurses, the lower their level of well-being and the higher their levels of job stress (both $p < 0.01$). The authors note that these findings were associated with emotional dissonance. Huynh *et al.* (2008) suggest that emotional dissonance is suggestive of surface acting.

Bartram *et al.* (2012) surveyed Australian nurses with the purpose of investigating the relationship between emotional labour, burnout, intention to leave, and the degree to which staff believed that they worked in a high performance work system. They found that emotional labour was positively associated with burnout and the intention to leave. However, working in a high performance work system had the effect of reducing the relationship between emotional labour and burnout. So while those who believed that they worked in a high performance work system still experienced emotional labour, their risk of burnout was lower than those who did not. These findings were particularly apparent when levels of emotional labour were high. Therefore, factors present in high performance work systems, such as 'job security, selective hiring, extensive training, teams and decentralized [sic] decision-making, information sharing, and transformational leadership', were associated with less burnout when high levels of emotional labour are experienced (Bartram *et al.*, 2012:1574).

In another survey with nurses, Schmidt and Diestel (2014) investigated the effect of emotional labour, in particular surface and deep acting, on absence from work as a proxy for job strain. They surveyed German nurses in a hospital and nursing homes and collected absence data for 12 months following completion of a questionnaire. The researchers found a positive association between surface acting and job strain but no association between deep acting and job strain. They reported that surface acting was also associated with burnout, depressive symptoms, and a great number of days absent from work.

A survey to understand the adoption of different emotional labour strategies (that is, surface or deep acting when nurses experienced different types of patient encounters) was conducted by Golfenshtein and Drach-Zahavy (2015). In this survey, paediatric nurses working in Israel completed a new questionnaire after multiple interactions with patients. The authors reported that nurses used more deep acting when they believed that they could influence a change in the stressful conditions related to the encounter, and more surface acting when they believed that there was little chance of promoting a change in the stressful interaction with the patient. Therefore, the authors suggested that nurses are more likely to distance themselves from patients in situations where they feel they have little control for facilitating change.

Chou *et al.* (2012), who conducted a cross-sectional survey with hospital nurses in Taiwan, concluded that nurses who undertook emotional labour

by using surface acting were more likely to have a higher interaction with 'difficult patients' compared to those who used deep acting. They also reported that support and job satisfaction were both positively associated with deep acting and negatively associated with surface acting. The authors created a non-validated 7-point Likert scale with 'four items' with which nurses indicated how much they agreed with the items (Chou *et al.*, 2012:505). However, the results only list three items: 'I do not interact with many difficult patients in my work; I interact with many complaining patients in my job; I deal with many difficult patients at work' (Chou *et al.*, 2012:507). A limitation of this study is that it is possible that nurses who deep act are less likely to perceive their patients as 'difficult' as deep acting enhances empathy (Larson and Yao, 2005; Burks and Kobus, 2012).

Tsukamoto *et al.* (2015) researched the association between emotional labour, health and job satisfaction in long-term care workers in Japan by the use of a mailed questionnaire. The respondents were a range of staff including, 'care staff', 'consult staff', 'nursing staff', and 'other staff' which are not defined (Tsukamoto *et al.*, 2015:817). The authors reported an inverse relationship between emotional labour and job satisfaction. They also reported both negative and positive effects of emotional labour on health and workplace satisfaction. The authors suggest that this may be because some staff had a positive response to emotional labour as they believed that it enabled them to provide high quality care. However, there

was no assessment of deep or surface acting, which may have better explained these findings.

Overall, the quality of these surveys was good. All the surveys used validated tools to collect all or part of the data. The response rates ranged from 100% (Golfenshtein and Drach-Zahavy, 2015) to 20% (Tsukamoto *et al.*, 2015), although not all the studies reported a response rate (Karimi *et al.*, 2014). The sampling strategies used enabled a representative sample to be recruited, for example, mailing all day care centres in Tokyo (Tsukamoto *et al.*, 2015) and attaching a questionnaire to all nurses' pay slips (Bartram *et al.*, 2012). The samples appeared to be representative of the larger population from which they were sampled, with sample sizes of up to 312 (Karimi *et al.*, 2014). Golfenshtein and Drach-Zahavy (2015) only had a sample size of 41; however, this was all the nurses on two wards, and they completed questionnaires related to 239 patient encounters over eight months, providing a large data set.

These surveys suggest that emotional labour was being undertaken by a range of staff, and that deep acting overall appears to be more beneficial than surface acting. Therefore, training to enable more deep acting may be beneficial. The surveys also highlight the need for staff to be supported.

Conclusions about emotional labour

The concept of emotional labour is important and should be recognised by staff and organisations as it has the potential to affect patients and staff.

How emotional labour is performed seems to be important, with surface acting broadly having negative effects and deep acting broadly having positive effects. Emotional labour can lead to staff distancing from emotional situations and to staff becoming desensitised, and there is an association between surface acting and decreased job satisfaction and burnout. Staff support and training may be of benefit. Emotional labour appears to be common in healthcare, but it has not been reported within dietetics before.

Emotional labour forms part of emotional intelligence (McKenna and Mellson, 2013; Cherry *et al.*, 2014), therefore it is useful to explore the concept of emotional intelligence.

3.5.4 Emotional intelligence

Definitions of emotional intelligence vary but most encompass being aware of one's own emotions, the emotions of others, and being able to regulate and manage those emotions (Arora *et al.*, 2010; Fox, 2013; McKenna and Mellson, 2013; Cherry *et al.*, 2014). Higher levels of emotional intelligence are associated with positive effects on empathy, teamwork, communication, doctor-patient relationships, leadership, and management of stress (Arora *et al.*, 2010). There is also debate about whether emotional intelligence is a trait, a skill, or a mix of both (Arora *et al.*, 2010; Cherry *et al.*, 2014; Foster *et al.*, 2015). However, as training appears to increase emotional intelligence, it seems likely that there is a

skill aspect to emotional intelligence (McKenna and Mellson, 2013; Cherry *et al.*, 2014).

While there is little clear evidence about the best approach to develop emotional intelligence, two themes have been recommended for training programmes: self-awareness training and social skills training. Self-awareness training includes developing skills in reflection and being aware of one's own emotions. Social skills training aims to develop empathy and, improve communication skills, and tries to help the health professional to better understand patients' concerns and emotions (McKenna and Mellson, 2013; Cherry *et al.*, 2014). Foster *et al.* (2015) recommend ongoing training for qualified staff to ensure continued high levels of emotional intelligence.

McKenna *et al.* (2013) and Cherry *et al.* (2014) recognise that emotional labour forms part of emotional intelligence. Therefore, display rules, which are the professional or organisational rules which dictate the appropriate displays of emotion (Ashforth and Humphrey, 1993), need to be considered during an analysis of emotional intelligence. Professional codes of conduct influence the display rules that a professional may feel they should follow (Grandey, 2000; Theodosius, 2008). Display rules can be taught or learnt through observation, and also through socialisation into a profession (Ashforth and Humphrey, 1993; Grandey, 2000; Smollan, 2006; Smith, 2012). There may also be social and cultural influences for display rules (Ashforth and Humphrey, 1993).

3.6 Advocacy in healthcare

Advocacy in healthcare includes advocating for patients, health policies, and organisations (O'Connor and Kelly, 2005; Ham, 2014; NHS England *et al.*, 2014; Swientozielskyj *et al.*, 2014). It involves protecting patients' rights and the empowerment of patients (Hanks, 2007). Patient advocacy means speaking up for the patient when they feel powerless or voiceless (Rasmussen, 2012), and in doing so advocacy can protect patient autonomy (Bu and Jezewski, 2007). Advocacy is therefore included in professional codes of conduct and is a key part of professional practice (Schwartz, 2002; Van De Camp *et al.*, 2004; Palermo, 2015; Health and Care Professions Council, 2016). The experiences of nurses' involvement in decision-making about ANH in dementia suggested that they were unable to advocate for their patients (Bryon *et al.*, 2012a), and it is possible that other professions also experience challenges with advocacy. Therefore, to inform my research, the recent literature about advocacy in healthcare professionals will now be considered.

3.6.1 Advocacy in nutrition and dietetics

Most of the published work about advocacy in dietetics is from North America, and are discussion or opinion papers related to advocating for public health nutrition policy or interventions (Bellis-Smith, 2000; Capra and Capra, 2000; Michael, 2005; Smith *et al.*, 2005; Smith, 2008; Rodriguez, 2010; Johnson-Askew *et al.*, 2011; Peregrin, 2011; Rodriguez, 2011). Booth and Smith (2001) highlighted the challenges of dealing with food poverty and food insecurity for Australian dietitians and the need for

dietitians to be advocates of change through changes in food policy. Other discussion papers have addressed the need to promote and advocate for dietetic services within healthcare (Laramee, 2004; Walton, 2009; Bergman, 2012; The British Dietetic Association, 2012d; Walton, 2012).

British guidelines and standards suggest that dietitians should be undertaking the role of an advocate (The British Dietetic Association, 2008a; The Scottish Government, 2012; The British Dietetic Association, 2013; Health and Care Professions Council, 2016). The National Collaborating Centre for Acute Care (National Collaborating Centre for Acute Care, 2006) suggests that nutrition support teams (made up of at least a dietitian, a doctor, a nurse specialist, and pharmacist) should advocate for patients. The BDA Curriculum Framework for the pre-registration education and training of dietitians states that dietitians should advocate for patients and public health policies, and to promote the profession. American guidance on ANH also notes the need for dietitians to advocate for their patients (O'Sullivan Maillet *et al.*, 2013; Brantley *et al.*, 2014); however, Brody *et al.* (2014) suggest that championing patients' needs is part of a specialist dietetic role for American dietitians.

There is a small amount of empirical research about dietitians and advocacy and on ANH and advocacy. An American survey from the 1970s reported that dietitians had positive attitudes to taking on this role, but not that they actually acted as advocates (Springer and Segal, 1975). Other empirical research investigated dietitians' involvement in advocacy for

nutrition-related policy. Mondelli *et al.* (2015) reported the results of a survey which aimed to recruit all the new entry-level dietitians in America. They concluded that entry-level dietitians had the skills needed to advocate for nutrition policies, although active involvement was low at 30%. While the reported response rate was 22% (n=3164), it is difficult to further assess the quality of this survey as it was only published as a conference poster. Another conference paper was published by Holliday *et al.* (2013). This report was a case study to show a successful advocacy campaign to promote the role of American dietitians within public health policy incentives. In other empirical research Dowding *et al.* (2011) interviewed 19 Australian graduate entry dietitians to explore their experiences of working with patients with mental health problems. While not specifically about advocacy, the authors noted that advocacy was one of the skills that dietitians used in their care of these patients.

Within the area of ANH, various authors have noted the need for patient advocacy within decision-making about ANH. Nelson *et al.* (2015) performed a systematic review of qualitative studies into families' experiences of gastrostomy tube placement in children with neurologic impairment. One aspect they reported was that parents felt that advocacy was needed when dealing with the medical system. Jenkins (2012) used a case study and interviews to consider the health and social care needs of people with learning disabilities. Based on his qualitative analysis of interviews, the author concluded that the health needs of these patients can be complex, and so advocacy could be difficult. He recommended that

healthcare professionals encouraged patients to self-advocate where able, and where this was not possible that independent advocacy services should be used rather than nurses taking on this role. Fairclough *et al.* (2008), in their guidance for dietitians about patients with learning disabilities who have long-term ANH at home, have also made recommendations about advocacy. They note that dietitians have a role in advocating for patients. However, situations can be complex and professional advocacy services may be needed.

As the literature about advocacy within dietetics is limited, and the literature review of experiences of decision-making about ANH in dementia identified difficulties with advocacy for nurses, I will now consider the literature related to nursing and advocacy.

3.6.2 Advocacy within nursing

Jugessur and Iles (2009) conducted a narrative review which explored the concept of advocacy within nursing. The authors outlined that nurses are expected to advocate for their patients by creating a supportive environment, giving information, helping patients understand risk and benefits, and by helping patients think about their own values and beliefs. The nurse may then need to communicate this to the rest of the team. The review also discussed the challenges of acting as a patient advocate; when a patient's wishes may not be expressed, which may lead to paternalistic advocacy. Other challenges described were related to the risks involved for a nurse when they needed to speak up about healthcare

inadequacies, for example, colleagues' poor practice, or limitations within an organisation. Although the focus of the review was nursing advocacy, Jugessur and Iles (2009) note that patient advocacy should not just be limited to nurses, as other health professionals can also undertake this role.

Toda *et al.* (2015) interviewed 21 Japanese psychiatric nurses to analyse the situations in which the nurses intervened to act as patient advocates. Their findings indicated that these were situations related to respecting patients' rights. Specifically these were situations related to patient safety, inhibition of patient decision-making, difficult patient behaviour inhibiting treatment, families inhibiting treatment, inappropriate reductions in patient liberty, and families taking advantage of patient property.

A review and meta-synthesis of nine studies into nurses' experiences of patient advocacy in the perioperative period was undertaken by Munday *et al.* (2015). The two themes reported were being the patients' voice in order to safeguard patients, with trust between patient and nurse an important aspect of this; and the challenges of patient advocacy, which can lead to workplace conflict and distress. They also suggested that barriers to being a patient advocate included a lack of experience and time pressures.

Barriers to nurses acting as patient advocates were also explored by Hanks (2007) in a concept analysis. He noted possible conflicts when nurses spoke up for patients against colleagues or their employers, and

that a lack of time to act as an advocate was an issue. He also cited a lack of support, lack of power, a fear of the repercussions of speaking out, and education as additional barriers to patient advocacy.

The effect of not acting as an advocate for patients was one of the factors that Barlem and Ramos (2015) considered in their narrative review of moral distress. They stated that nurses face barriers to patient advocacy, such as feelings of powerlessness and organisational obstacles. These may result in a failure to fully advocate for a patient in a way which the nurse may be satisfied with, which can lead to moral distress.

Law and Chan (2015) undertook unstructured interviews with 18 newly qualified nurses in Hong Kong to investigate their experiences and reflections of moving from being a student to a qualified nurse. Three of these nurses reflected on the need to advocate for their patients by speaking up. They were prompted to speak up by their professional identity of being a good nurse and needing to protect their patients. A supportive environment, positive role modelling, and space to think and talk through how it would be best to deal with the situation all facilitated the nurses to speak up and to advocate for their patients.

These studies used different methodologies to explore this issue within nursing to give a broad view of the concept. Two of the review articles included thorough searches to retrieve appropriate studies to address the studies' aims (Hanks, 2007; Munday *et al.*, 2015). However, the other

reviews (Jugessur and Iles, 2009; Barlem and Ramos, 2015) did not include a search strategy so it is possible that these reviews are not comprehensive or without bias. Rigour was enhanced in the qualitative research by prolonged contact with the participants (Law and Chan, 2015) and use of case examples to clearly illustrate the findings (Toda *et al.*, 2015). However, neither of these studies addressed the position of the researcher and how this might have affected the study. The external validity of the research also needs to be considered, as the qualitative research was conducted with nurses from Japan and Hong Kong. However, the review by Munday *et al.* (2015) included studies from America, Australia, the UK and Sweden.

3.6.3 Summary

Advocacy is a key aspect of professionalism for healthcare professionals, and can consist of advocating for health policy, advocating for health services, and advocating for patients. Power is needed to advocate, in order to speak up and be heard. For some nurses advocacy was linked with their professional identity of being a good nurse, and when patient advocacy was unsuccessful, some nurses experienced moral distress. It is likely that patient advocacy may be needed when working with people receiving ANH, although to date there is little empirical research about dietitians acting as a patient's advocate.

As power, professional identity, and professionalism are all aspects associated with advocacy, it suggests that issues related to interactions

between professional groups may be important. Therefore, the sociology of health professions will now be considered.

3.7 The Sociology of Health Professions

3.7.1 Introduction

The literature reviewed so far suggests that there may be professional implications for those involved in decision-making about ANH, for example, the ability to act as an advocate as part of professional practice (Schwartz, 2002; Van De Camp *et al.*, 2004; Palermo, 2015; Health and Care Professions Council, 2016). To consider how the experience of decision-making may influence professional practice, I will now consider the sociology of health professions, specifically in relation to professional practice, such as division of labour, hierarchy, and team working, all of which are likely to impact on the experiences of involvement in decisions about ANH.

I will start this section by defining what professions are, and move onto the development of dietetics as a professional group, and the status of dietitians. I will then consider hierarchy and medical dominance within healthcare settings, and the importance of team working. This review of the sociology of health professions will end by exploring professionalism and how it may be conceptualised within professional practice.

3.7.2 Professions

The Pocket Oxford English dictionary defines a profession as a vocation or

calling, especially learned or scientific, and gives the example of the medical profession (Thompson, 1996). Others have defined health professions in more detail. Health professions undergo training to develop specific abilities, expertise, knowledge, and skills in order to undertake some kind of special work (Berman Brown and McCartney, 2002).

Freidson (1994) suggests that professions have control over their work, therefore they have autonomy. Patients put their trust in their healthcare professionals, as the knowledge and skills used to care and treat may not be totally understood by patients (Berman Brown and McCartney, 2002).

Healthcare professions are governed by ethical codes (Beaton, 2010), and need to be able to use their skills and knowledge to make decisions, therefore discretionary judgement or autonomy is required (Freidson, 1970; Berman Brown and McCartney, 2002). However, the degree of discretionary judgement and autonomy that a healthcare professional has varies within healthcare settings, with doctors seen as the dominant profession, as they 'order' treatments and have authority over these tasks (Freidson, 1994). The autonomy of dietitians will be explored in the next section.

Social closure is also an aspect of the professions. This is the process of regulating admission to a profession by the process of registration or by obtaining a licence to practise (Rees Jones, 2003; Hyde, 2013). This registration, obtained through training and assessment to ensure competence, provides jurisdiction over a set of tasks and ensures safe practice (Freidson, 2013). It also acts as a way of controlling professional

services by way of legislation, as without this registration membership to the profession is closed (Abbott, 1988; Freidson, 2013).

3.7.3 Professionalisation of dietetics

The profession of dietetics developed from nursing; the first dietitians were nurses, who adopted the role of so-called 'sister dietitians' in the 1920s (Hutchinson, 1961:6). These first sister dietitians implemented doctors' orders for patients' therapeutic diets. As the roles developed and the number of sister dietitians increased, it became apparent that the role of the dietitian needed to be more clearly defined and there needed to be a standardised course of training to become a dietitian. This led to the establishment of The British Dietetic Association in 1936 (Hutchinson, 1961).

The training, practice, and registration of dietitians developed further when the 'Professions Supplementary to Medicine Act' received the Royal Assent in 1960, leading to the development of the Council for Professions Supplementary to Medicine who oversaw the training and registration of dietitians (Bateman, 1986). Thus it could be argued that dietitians were professionalised by nature of their specific training, their professional association, and the need to be registered. Prior to this there was a volunteer register for dietitians with the Board of Registration of Medical Auxiliaries (Health Professions Council, 2012). Thus in the 1960s dietitians moved from being viewed as a 'medical auxiliary' to a 'profession supplementary to medicine'. As such there was a recognition of the

professional status of dietitians. However, it still suggested that dietitians had a subordinate role to doctors: indeed the code of conduct for dietitians at that time stated that dietitians could only advise patients with a medical referral (Health Professions Council, 2012).

There has been a move away from the term 'profession supplementary to medicine', with the term 'allied health professional' now being used, which recognises the role of other professions within healthcare and a less central and less dominant role of medicine (Bradby, 2009; Elston and Gabe, 2013). Indeed, the latest standards of proficiency for dietitians state that dietitians are autonomous professionals who should exercise their own professional judgement (Health and Care Professions Council, 2013). Just recently, dietitians have been granted supplementary prescribing rights (Allied Health Professions Medicines Project Team, 2016), so developing their autonomy further. So over the last 90 years dietitians have developed from a medical auxiliary role to one of an autonomous allied health professional (Health Professions Council, 2012).

The degree of autonomy that dietitians have with regard to ANH is open for debate. While dietitians are experts in nutrition (Andrews, 2004; Chakladar, 2012), and may make autonomous decisions about the type, amount, and rate of enteral feed, as outlined in section 2.4, doctors do have the ultimate responsibility for the decision to feed or not. However, there is a range of guidance for doctors which indicates that other healthcare professionals, such as dietitians, should be involved in these

decisions. The guidance states that doctors should involve other healthcare professionals in discussions with patients as appropriate (General Medical Council, 2008), doctors should ensure that healthcare professionals can contribute to decision-making (General Medical Council, 2012), and doctors should involve healthcare professionals in decision-making if the patient does not have capacity (General Medical Council, 2008). In end-of-life care, the General Medical Council states that healthcare professionals should be contacted if they have relevant knowledge and experience which can help in treating the patient (General Medical Council, 2010). Guidance by the British Geriatrics Society on the management of dysphagia recommends that advice should be sought from dietitians, and that they should be involved in the team decisions made (Chakladar, 2012). So while dietitians may not have ultimate autonomy over decisions to feed or not, good practice suggests that they should be involved in inter-professional decision-making.

3.7.4 The professional status of dietetics

There is some research which can give an insight into the professional status of dietitians. In the UK, Stanley and Borthwick (2013) interviewed six dietitians who worked in home enteral feeding services. They all took on extended roles, which included changing feeding tubes. One of the themes from the research was that the dietitians believed that there had been an increase in their professional status as a result of taking on these extended roles (Stanley and Borthwick, 2013). There is also some UK evidence regarding the public perception of dietetics. Crocker's (2000)

conference abstract reported that Scottish public awareness of dietitians was poor, with 26% of the 165 subjects questioned believing that dietitians distributed and collected the hospital menus and that 21% thought that dietitians prepared the meals in hospital. The subjects reported that they would get their nutritional information from doctors, practice nurses, and health food shops rather than a dietitian. Of course this research is now 16 years old, so the public perception of dietetics may have changed.

As there is a lack of research in this area with UK dietitians, research from other countries has also been reviewed, but as these may have different organisational structures to the UK, they may not fully reflect the status of UK dietetics. However, studies from other countries have indicated that dietitians may not have a positive view of their own status. Szeto *et al.* (2014) report that 45% of the Canadian dietitians who responded to their survey were dissatisfied with their role, and approximately 33% felt occasionally or rarely supported in the workplace. Approximately 47% occasionally, rarely, or never felt that everyone's feelings were taken into account during decision-making about PEGs.

These findings are in contrast to the other findings about job satisfaction within dietetics in America and Australia, which is generally reported to be good (Kolodny and Chan, 1996; Mortensen *et al.*, 2002; Osland, 2014). Being recognised as an expert, being respected, working collegiality, being recognised by the team, working on challenging cases, taking on more responsibility, and being involved in decisions were all aspects

reported to have positively influenced job satisfaction for dietitians in America, Canada, New Zealand and South Africa (Wildish, 2001; Devine *et al.*, 2004; Pratt *et al.*, 2005; Cody *et al.*, 2011; Visser *et al.*, 2012; Szeto *et al.*, 2014).

Community dietitians from America and South Africa reported a lack of respect from colleagues, suggesting that they may have been viewed as having a low status (Devine *et al.*, 2004; Visser *et al.*, 2012). Visser *et al.* (2012) suggested that the South African dietitians may have experienced disrespect or disregard by other professionals because dietitians were not assertive, or that their colleagues may not have understood the benefits of dietetic interventions. Overall, they concluded that the status of South African dietitians needed to improve.

The Canadian dietitians who completed the survey for Szeto *et al.* (2014) give an insight into their perceived status. The results show that the majority of dietitians (83.1%) indicated that there was always or usually respect between dietitians and doctors; 75.3% reported to always or usually feeling supported by doctors. However, it is important to note that most of these dietitians were senior dietitians working in specialist areas.

Much of this research was collected via surveys, so issues such as sampling and response rates need to be considered. Some researchers attempted to sample all dietitians in their target population. For example, Visser *et al.* (2012) sent their survey to all registered dietitians in South

Africa, while others randomly sampled from their target population (Mortensen *et al.*, 2002). Responder bias is likely to be an issue in all the surveys as the response rates varied from 19.9% (Szeto *et al.*, 2014) to 50.8% (Mortensen *et al.*, 2002). However, sample sizes are likely to be adequate to represent the sampled population of some studies, for example, 1668 in Osland *et al.* (2014). Two studies collected data qualitatively to give a deeper insight into job satisfaction (Devine *et al.*, 2004; Cody *et al.*, 2011). Again, the generalisability of this data does need to be considered, as it was collected from dietitians outside the UK.

Dietetics is a female-dominated profession, with about 95% of registered dietitians being female (personal communication email Health Professions Council 2010). The influence of gender on status and power is complex. Lichtenstein *et al.* (2004) conducted a survey with multi-disciplinary teams and concluded that male team members felt they had higher levels of influence within the team than female team members. Within nursing, power and gender have been widely considered (Manojlovich, 2007). Mackay (1993) reported that there were differences in the experiences of male and female nurses in British hospitals. Male nurses felt more equality with doctors and more able to speak up than female nurses. In contrast to this Khokhe *et al.* (2009) found in their Canadian study that it was organisational culture of the work unit rather than gender *per se* which affected experience, as female doctors and midwives did not experience the same tensions and frustrations as female staff nurses. Therefore, gender and organisational culture may have an influence on perceptions

of power and influence. Also in Canada, Zelek and Phillips (2003) conducted a survey with female nurses to explore their relationships with doctors. They concluded that nurses reported different relationships depending on the gender of doctors, with the reported power imbalances between nurses and male doctors reduced when the doctors were female. Thus, gender and hierarchy seemed to have an influence on power. Hierarchy and medical dominance will be explored in the next section.

3.7.5 Medical dominance in health settings

Friedson's (1970) seminal work 'professional dominance, the social structure of medical care' is much cited in discussions of health professions (Cott, 1997; Mead and Bower, 2000; Nancarrow and Borthwick, 2005; Reeves *et al.*, 2009; Nugus *et al.*, 2010). Friedson's (1970) work explored the dominant role of doctors in relation to other healthcare professionals. In this work, authority, autonomy, and dominance are key aspects, that is, the power doctors have over their own work and practice (their autonomy), and the dominance they have over other healthcare professionals (Rees Jones, 2003; Elston and Gabe, 2013). Friedson's (1970) analysis of healthcare suggested that services are organised around doctors and their professional authority. Friedson (1970) also noted that there was a gradual dominance of medicine over other healthcare areas, as demonstrated when healthcare professionals follow doctor's 'orders'. Friedson (1970) also suggested that this dominance was for the professional group as a whole (that is, medicine) rather than individuals within that profession, so the whole group was

perceived as dominant.

Friedson's (1970) analysis also explored the division of labour within healthcare through the principles of medical dominance and professional autonomy. Professional autonomy relates to the 'control over the content and terms of work' (Freidson, 1970:134), and is related to division of labour. If the dominant profession (medicine), 'orders' a treatment, test, or care, and that order is followed, the professional autonomy of the person following the 'orders' may be reduced, as they lack control and have reduced discretionary judgement. Of course, the health professional may agree with that 'order' or treatment plan, but literature about decision-making and moral distress suggests that healthcare professionals do follow 'orders' they do not agree with (Norberg *et al.*, 1987; Day *et al.*, 1995; Bryon *et al.*, 2010). Consequently, Friedson (1970) questions whether other healthcare groups can have the status of a professional group if they lack autonomy. As previously outlined, it could be argued that dietitians have autonomy over some decisions related to ANH, but not the ultimate decision to start or withdraw ANH.

Friedson's (1970) theory of professions within medical care was mainly focused on the American healthcare system and may not apply in the same way to a 21st-century British health system. Indeed, in his later writing Friedson stated that medicine has lost some of its dominance within healthcare settings (Freidson, 2013). Elston and Gabe (2013) have suggested that the medical power noted in the 1970s may not be so

appropriate now. This reduction in medical power and medical dominance seems to have come from changes in health structures, management changes, a move to more evidence-based practice and use of guidelines, treating more educated patients, and a less paternalist approach to patients (Sullivan, 2000; Rees Jones, 2003; Gabe *et al.*, 2006; Bradby, 2012; Elston and Gabe, 2013). Healthcare professionals receiving supplementary prescribing rights have also had an effect on reducing the dominance of doctors (Borthwick *et al.*, 2010). Indeed, it has been suggested by some that doctors now share power with other healthcare professionals (Måseide, 2013). However, empirical research and literature reviews suggest that this sharing of power is incomplete, as reports of medical dominance and hierarchy still prevail in the literature (Marquis and Gayraud, 2002; Goodrich, 2011; Monrouxe *et al.*, 2011; Youngwerth and Twaddle, 2011; Grace and Trede, 2013).

3.7.6 Professional boundaries

Within healthcare settings, different healthcare professions take on different professional roles, that is, there are occupational divisions. Some professions have full jurisdiction over their roles, while others may have subordinate jurisdiction (Abbott, 1988). There may also be overlaps within these roles, or one profession may view a role as their job, which can lead to conflict (Abbott, 1988; MacDonald, 1995; King *et al.*, 2015). With increasing pressures on healthcare delivery in terms of costs, staff shortages, and skill mix, traditional roles have shifted and so have traditional work boundaries. Health professionals have developed new

skills and adopted new roles normally undertaken by others (Fournier, 2002; Niezen and Mathijssen, 2014); this has resulted in some professional groups taking on extended roles. The extension of roles has enabled some groups to demonstrate their knowledge and their jurisdiction over tasks, which may lead to an improvement in their professional status and enhance their autonomy (MacDonald, 1995; Powell and Davies, 2012; Freidson, 2013).

However, there can be resistance to these shifting professional boundaries, and some suggest that health professionals actively work to defend their boundaries and maintain their jurisdiction over their clinical work (Fournier, 2002). Conflicts can arise when professions extend their boundaries to adopt roles normally delivered by others. King *et al.* (2015) note that these boundary disputes are common when non-medical professions seek to acquire roles from doctors. Professionals want to protect or control these areas to maintain their roles, power, and status (Niezen and Mathijssen, 2014). Giving up these roles means sharing knowledge or accepting that others also have this knowledge, which might affect their status. To maintain power, professional groups may attempt to prevent others from expanding their boundaries into their own by using their professional knowledge and skills, and by refining problems, to argue that an area of practice should be theirs as it is within their area of competence (Fournier, 2002).

Power will influence how effective professions are at defending their

jurisdiction and expanding their boundaries. Perhaps because of their traditional dominance within healthcare systems, and their high levels of autonomy, medicine has been better at expanding their boundaries and so maintaining their status than other healthcare professionals (Powell and Davies, 2012; Stanley and Borthwick, 2013). However, other professions have managed to extend their boundaries and extend their roles to take on jobs traditionally undertaken by doctors (Rees Jones, 2003), for example, the development of nurse practitioners who prescribe (Niezen and Mathijssen, 2014) and community dietitians extending their roles to change feeding tubes (Stanley and Borthwick, 2013). Interestingly, the dietitians interviewed in the study by Stanley and Borthwick (2013) believed that doctors were supportive of this extended role, but nutrition nurse specialists experienced this as boundary conflict and jurisdictional competition.

3.7.7 Empowerment of professions

Empowerment can be hard to define, but it is generally understood that empowerment enables one to act and undertake a course of action (Manojlovich, 2007; Bradbury-Jones *et al.*, 2008). As autonomy is a key aspect of being in a profession (Freidson, 1970) and of professional practice (Health and Care Professions Council, 2013), empowerment is therefore directly related to the concept of professionalism. Empowerment is also related to having an influence (Kuokkanen and Leino-Kilpi, 2000) and an impact (Kuokkanen and Leino-Kilpi, 2001), therefore empowerment should enhance professional practice and professional

development (Kuokkanen and Leino-Kilpi, 2000; Kuokkanen and Leino-Kilpi, 2001; Faulkner and Laschinger, 2008; Wagner *et al.*, 2010).

Empowerment may also have additional benefits of increasing job satisfaction, increasing perceptions of respect, increasing organisational commitment and innovation, reducing effort-reward imbalance, and reducing burnout (Wagner *et al.*, 2010; Trus *et al.*, 2012; Cicolini *et al.*, 2014). It may also reduce moral distress (Browning, 2013).

The three most recent systematic reviews of empowerment in healthcare have all investigated the concept of empowerment within nursing (Wagner *et al.*, 2010; Trus *et al.*, 2012; Cicolini *et al.*, 2014). Their analysis of empowerment mainly focused on structural empowerment and psychological empowerment. Structural empowerment is related to organisational structure and hierarchy, and factors such as work opportunities, having adequate resources, support, and access to information (Wagner *et al.*, 2010; Trus *et al.*, 2012; Cicolini *et al.*, 2014). Psychological empowerment is related to competence and confidence, autonomy and control, the match between personal values and the requirements of a job, and a sense of having an important work role (Wagner *et al.*, 2010; Trus *et al.*, 2012; Cicolini *et al.*, 2014). It appears that structural empowerment is needed before effective psychological empowerment can develop (Wagner *et al.*, 2010; Cicolini *et al.*, 2014).

Trus *et al.* (2012) reviewed the literature related to nurse manager empowerment. They reported that nurse managers had high levels of

empowerment, and the level of perceived empowerment was associated with the nurse's position within the organisation. Empowerment was enhanced by involvement in management decisions, development of expertise, and having responsibility for practice. Structural factors which enhanced empowerment included opportunities for development, being recognised for their work contribution, and gaining positive feedback. Cicolini *et al.* (2014) investigated nurse empowerment and job satisfaction. They reported a positive relationship between empowerment and job satisfaction, and the importance of a satisfying work environment for nurse empowerment. Finally, Wagner *et al.* (2010) explored empowerment in nurses. Their review concluded that an organisation which provided structural empowerment contributed to the psychological empowerment of nurses. This resulted in increased job satisfaction and reduced burnout for nurses. While all these reviews conducted comprehensive searches, there was not a wide empirical literature on which they could base their findings, and many studies came from one group of researchers based in Canada.

3.7.8 Teamwork

Teamwork is central to professional practice and so is part of the sociology of professions (Witz and Annandale, 2006). Teamwork is also likely to have an influence on healthcare professionals' experiences of decision-making about ANH. For example, nurses have reported that they felt they worked in hierarchical environments, that they did not feel they were consulted about decisions related to ANH, and felt they were not part of the team (Bryon *et al.*, 2010; Bryon *et al.*, 2012a). Team working is an

important aspect of empowerment (Laschinger and Havens, 1996; Kuokkanen and Leino-Kilpi, 2001; Faulkner and Laschinger, 2008).

Team working in the provision of ANH has been investigated by Makka *et al.* (2014). They conducted a systematic review to explore how different care delivery models affected patient and staff outcomes, and hospital costs for patients receiving ANH. Specifically, they investigated care delivery models that used care coordination and/or team approach methods for patients requiring long-term enteral tube feeding in any setting outside of a hospital. They included 15 studies in their review which included a range of different team members, (doctors, specialists, nurses, dietitians, and speech and language therapists). The interventions were varied and were composed of different strategies, such as education to patients, family, and staff. These also included team coordination, for example, having a team leader and regular team meetings.

Overall, there were improvements in patient outcomes, staff workload, and hospital costs. However, a meta-analysis did not report any improvements in rates of complications, infections, or hospital admissions, although there was a reduction in hospital cost ($p < 0.01$). So while care coordination through a multi-disciplinary team appeared to have overall benefits due to the multiple components of the inventions, it is not possible to draw further conclusions about team mix or specific interventions.

The review by Majka *et al.* (2014) is of good quality. They appear to have conducted a broad search to capture relevant studies by searching seven databases, searching for reviews and guidelines, and by consulting with experts. The researchers included any empirical study design if it included outcomes of interest. Studies were assessed for quality using standardised tools; however, the quality of the majority of the reported studies was low.

Two studies have been published since this review which expand the evidence base a little. Ogita *et al.* (2012) conducted a cross-sectional survey of all the board-certified geriatricians in the Japan Geriatrics Society to explore whether a team approach affected decision-making and interventions for dysphagia. They had 555 useable questionnaires, with a response rate of 44.4 %. The authors conclude that a multi-disciplinary approach was desirable when making decisions about ANH, as the doctors who used a team approach used a greater number of other strategies (for example, using thickened fluids) before considering tube feeding, compared to the comparison group. The external validity of this research must be considered as it was conducted in Japan, where at the time of the research there were no clear guidelines about the use of ANH in conditions such as dementia.

In the UK Clarke *et al.* (2014) conducted a retrospective review of patients referred to a multi-disciplinary feeding issues team over a one-year period. Their clinical review of 158 cases indicated that 28% (or 44 patients)

lacked capacity for decision-making. Due to the complexities around making decisions for patients who lack capacity, the authors concluded that multi-disciplinary teams provide a suitable forum and space for discussion of the relevant issues. While of interest, the conclusions of this study are based on expert opinion rather than improvement in outcomes when a team approach is used.

The results of the review by Majka *et al.* (2014) were that overall teamwork and care coordination has positive effects on outcomes and is supported by others who promote team working within healthcare practice (National Institute for Health and Clinical Excellence, 2006; Vesey *et al.*, 2008; del Río *et al.*, 2012; Health and Care Professions Council, 2013; Clarke *et al.*, 2014). However, team working can be a challenge for healthcare professionals due to communication problems related to professional boundaries and hierarchies (Jasper and Rosser, 2013). Good communication and teamwork are just two aspects that influence professional behaviour. In the next section I will consider the literature on traits which contribute to professional behaviour and the different definitions of professionalism.

3.7.9 Definitions of professionalism

Professionalism is multifaceted and can be a difficult concept to define (Morrow *et al.*, 2011; The Scottish Government, 2012), but is generally recognised when it is seen (Arnold and Stern, 2006). Freidson (2013) states that professions need a range of skills and knowledge and their

decisions are made based on their own discretionary judgement. As well as skills, knowledge, and expertise, professions also need to be virtuous, trusted, and altruistic (Beaton, 2010). A literature review conducted by Wilkinson *et al.* (2009) identified five clusters of professionalism for health professionals: 'adherence to ethical practice principles; effective interactions with patients and with people who are important to those patients; effective interactions with people working within the health system; reliability; and commitment to autonomous maintenance/improvement of competence in oneself, others, and systems' (Wilkinson *et al.*, 2009:553).

Rogers and Ballantyne (2010) also reviewed the literature to analyse accounts of professionalism. They then refined their analysis by reviewing complaints to the Medical Board of South Australia for unprofessional behaviour and of any disciplinary action taken. By undertaking this process Rogers and Ballantyne identified five slightly different areas of behaviour which need to be considered when thinking about professionalism: 'taking responsibility; relationships with and respect for patients; probity and honesty; self-awareness and capacity for reflection and collaboration, and working with colleagues' (Rogers and Ballantyne, 2010:253).

While both these reviews identified common features of professionalism, they did not come to one definitive definition. These reviews may have come to slightly different conclusions because they had slightly different

aims. The review conducted by Wilkinson *et al.* (2009) aimed to aid the assessment of medical students' professionalism through the mapping of elements of professionalism to current assessment tools, while Rogers and Ballantyne's (2010) review aimed to clarify the definition of professionalism. While both these studies were related to professionalism within medicine, it is likely that they also apply to other healthcare professionals as similar aspects have been identified in reports on professionalism by the Health and Care Professions Council (2015b) and the Scottish Government (2012).

3.7.10 Threefold model of professionalism

The concept of professionalism has been explored by the use of a threefold model of professionalism developed by Van De Camp *et al.*, (2004). This model proposed three facets to professionalism: intrapersonal or individual, interpersonal, and societal–institutional or public (Van De Camp *et al.*, 2004). (See Table 5 for details of the three facets.) The first step in developing the model was for the authors to undertake a systematic review of the literature to identify any literature which described or defined professionalism and its related constituent elements. The review identified 57 papers including empirical research, opinion pieces, and guidance on professionalism from medical associations and committees. From these articles the authors undertook an analysis to identify key themes of professionalism. The themes were then validated using an expert panel.

Overall, the methodology adopted by Van De Camp *et al.* (2004) was appropriate. They used a range of search terms to conduct a sensitive search to retrieve literature for review; however, only one database (Medline) was used. While this is one of the main databases for medical journals, it is unlikely that a comprehensive search can be conducted by searching just Medline (Higgins and Green, 2011). However, this limitation was mitigated by the authors also undertaking reference checking of the retrieved articles. The expert panel broadly agreed with the themes, although they did question the relevance of the 'appreciation of literature and arts' and 'understanding history' to professionalism. The authors described this multi-disciplinary panel as having 'expertise [sic] and experience in teaching attitude and conduct at the department of postgraduate training for general practice' (Van De Camp *et al.*, 2004:697), and were two physicians, one medical sociologist, and two psychologists. So while the threefold model was endorsed by the panel, having the model endorsed by a panel external to the authors would further validate the model. However, Van De Camp *et al.* (2004) suggested that their model was useful for conceptualising professionalism in medicine across a range of career stages.

The threefold model of professionalism was reviewed and endorsed by an international working group of 18 experts who undertook a discourse analysis of professionalism (Hodges *et al.*, 2011). This panel was developed by inviting individuals who had published or spoken about medical professionalism internationally to form the 'International Ottawa

Conference Working Group on the Assessment of Professionalism' (Hodges *et al.*, 2011:354). The 18 experts were from nine different countries and included a mix of disciplines, that is, physicians, sociologists, psychologists, and educationalists. The expert group used an iterative approach to refine multiple drafts of their findings which were then disseminated for wider review by presentation at medical conferences in America and the UK. Comments were also invited via the International Ottawa Conference website. The expert group used feedback from these sources to make further refinements to their assessment of professionalism, and concluded that the threefold model captured and represented the current key aspects of professionalism in medicine (Hodges *et al.*, 2011). Again, this group was looking at assessment of professionalism in medicine, therefore it is important to assess whether this conceptual framework is valid for other professional groups.

Burford *et al.* (2014) assessed whether the threefold model was a suitable conceptual framework to assess professionalism in groups other than medicine. They conducted focus groups with students and educators from the disciplines of occupational therapy, podiatry, and paramedic care. The research aimed to explore: what is professionalism?; how does professionalism develop?; and whether their findings fitted with the threefold framework of professionalism. They concluded that their findings did map to the threefold model of professionalism. However, the authors cautioned that when the model is used, it is important to remember that the principles of the threefold model could overlap and are really a

continuum from the individual to the interpersonal, and finally the public and all three principles should be considered equally important in any analysis of professionalism.

Although three different professional groups were used in this research to give a broader perspective, it must be noted that educators' views may differ from those in clinical practice. In a discussion piece about the research, Chandratilake (2014) is of the view that it does identify the core areas of professionalism within these professions. Burford *et al.* (2014) concluded that as the model was a suitable conceptual framework to assess professionalism in these healthcare professions, it was likely to be suitable to use in other professional groups.

Marais *et al.* (2012) used the threefold model of professionalism to identify which aspects of professionalism South African dietetic students believed were important and relevant for their profession. They asked 109 students from two different universities to rate elements of professionalism from the threefold model from 'least agree' to 'most agree'. They found that the aspects that dietetics students selected as most important were the same as that of medical students; that is, communication skills, honesty, good clinical judgement, protection of confidential information, to respect rights of patients in shared decision-making, and trust (Marais *et al.*, 2012:32). The least important were an appreciation of literature and arts, and an understanding of history. Interestingly, the relevance of these to professionalism were both questioned by the experts in the research by

Van De Camp *et al.* (2004).

The response rate to this study was 67%. The sample included students from all four years of the course, although the views of students differed slightly between the four years, with third-year students viewing interpersonal aspects of professionalism more highly than public and intrapersonal aspects. While the threefold model enabled the views of dietetic students to be explored, it should be noted that the views of practising dietitians in South Africa may vary.

To summarise, the threefold model of professionalism developed by Van De Camp *et al.* (2004) has been endorsed by experts in medical professionalism (Hodges *et al.*, 2011) and appears to be a suitable conceptual model of professionalism for use in other healthcare groups (Marais *et al.*, 2012; Burford *et al.*, 2014).

3.8 Implications for the literature review for this study

The literature review has highlighted the lack of published research about dietitians' experiences of ANH and there is clearly an important gap in the literature. While there is a lack of research about dietitians' experiences around decision-making, what research there is suggested that there appeared to be gaps in dietitians' knowledge about the benefits of ANH and of the guidance on withdrawing ANH. It also showed that some dietitians believed that they were not adequately involved in the decision-making process. There are, however, studies of doctors' and nurses'

experiences around decision-making regarding ANH. This body of literature on other health professionals' experiences has identified important themes. These included gaps in knowledge, the varied influences on decision-making, the complexity of decision-making about ANH, and the emotional effects related to decision-making.

Gaps in healthcare professionals' knowledge about the indications, benefits, and harms of ANH might have implications for team working and information giving to patients and family. Factors affecting decision-making about ANH appeared to include the influence of team members, family, environment, and religion. Some healthcare professionals felt pressured to do things they would rather not do, suggesting moral distress. Clearly, there were emotions involved in these situations, namely feeling powerless, frustration and anger (when not involved in decisions that healthcare professionals thought they should be involved with), and feelings related to conflict due to uncertainty. Some healthcare professionals experienced emotional labour.

The reviewed literature highlights some key concepts and experiences which may be of importance for dietitians. These include hierarchy, autonomy, advocacy, team working, and team decision-making. The literature also highlighted the concepts of emotional labour and moral distress within decision-making about ANH. It was important, therefore, to explore these concepts in relation to dietitians. All these concepts relate to professional practice and professionalism, therefore a theoretical

framework of professionalism, particularly the threefold model as discussed in section 3.7.10, appeared to be a suitable theoretical framework within which to explore dietitians involvement in decisions about ANH.

It is important not to extrapolate the findings from the reviewed literature to other settings or professional groups. It should also be noted that many of the studies are non-UK based, where health structures may be different to the UK, and there may be issues with selection bias. Also, just because one professional group reported a particular experience, it does not necessarily mean that dietitians also will. However, the findings from the literature review offer a conceptual framework that can be incorporated into this study, as the concepts of team working, team decision-making, hierarchy, autonomy, advocacy, and emotions are likely to resonate with dietetic practice.

Dietitians have an important role in decision-making about ANH, and little is known about dietitians' experiences, so this is an important area to investigate. Therefore given the lack of research with dietitians, and the concepts identified from this literature review, the research question guiding this research was 'What are dietitians' experiences of being involved in decisions relating to ANH?' To answer the research question, the objectives guiding this research were:

- To explore dietitians' perceptions of their role in decision-making about ANH.

- To explore how different contexts influence dietitians' experiences of decision-making about ANH.

To fully consider how the aim and objectives of this research were achieved, the next chapter will discuss the methodology and methods adopted in this research.

Chapter 4: Methodology

4.1 Introduction

I have shown that there is an important gap in the literature about dietitians' experiences, which this study has aimed to address. The research question guiding this research was 'What are dietitians' experiences of being involved in decisions relating to ANH?' To answer the research question, the objectives guiding this research were:

- To explore dietitians' perceptions of their role in decision-making about ANH.
- To explore how different contexts influence dietitians' experiences of decision-making about ANH.

This chapter will now describe why an interpretative phenomenological approach was adopted for this research and will show how the methods chosen for this research are aligned with this methodological approach. It will outline the ethical considerations for this research, and demonstrate how rigour was maintained. However, this chapter will start by considering types of research knowledge.

4.2 Types of research knowledge

With the aims and objectives of the research stated, this thesis will now explore the nature of research and which research methodology was best to explore these aims and objectives. Research has been defined as a 'systematic and rigorous process of enquiry which aims to describe phenomena and to develop and test explanatory concepts and theories'

(Bowling, 2009:1). This definition gives an indication of the continuum of research and knowledge development; the description of phenomena which can lead to further developments which can be tested. These can be described as deductive or inductive approaches. Inductive approaches collect observations to develop ideas, whereas deductive approaches take ideas and test them to develop theory (Bowling, 2009). Deductive approaches make assumptions that data can be measured and observed and that there is one truth that can be tested.

4.2.1 Research paradigms and strategies

Research paradigms are the beliefs and assumptions that researchers hold, which are related to their disciplines, and will influence how research is conducted and interpreted (Barron, 2006; Bowling, 2009). The two dominant research paradigms are quantitative and qualitative approaches (Barron, 2006). Quantitative researchers measure observable objects which might be manipulated, and believe that one objective reality or truth can be tested and obtained (Barron, 2006; Bowling, 2009). For quantitative researchers it is only observable 'facts' which are of interest. They do not attempt to measure the meaning which people may attach to phenomena, as they do not believe that these can be objectively measured (Trochim, 2006). Quantitative researchers also believe that research conduct should be strictly controlled with bias controlled for, and that the researcher should not influence the research process. For quantitative researchers, from an epistemological view, knowledge is that which can be measured and observed and ontologically there is one truth.

A limitation of quantitative research is that it does not give insight into behaviour, emotions, and thoughts. It does not help us to understand why people do what they do or understand social interactions.

For qualitative researchers, observations will be influenced by social and cultural factors of the participants and researchers. Knowledge is constructed via the viewpoint of the researcher or the participant based on their worldview, and often this is co-constructed between researcher and the participants (Trochim, 2006). The researcher is not aiming for an objective measure, as knowledge is constructed and influenced by the social environment, so no one truth will be revealed, as there may be multiple realities. Ormston *et al.* (2014) note that some criticise qualitative research for being a soft science. Others have likened it to journalism, in that it lacks scientific rigour (McBrien, 2008). Some of these criticisms relate to variables not being controlled for as they can be in quantitative research. One such variable is the researcher, because in qualitative research the researcher is the primary data collection tool and analyser of the data (Merriam, 2014).

As briefly outlined above, both methodologies have strengths and limitations, therefore one research paradigm is not necessarily better than another. As a consequence there have been calls to move beyond the traditional hierarchies of quantitative research being seen as gold standard research and take more of a pragmatic approach to research inquiry (Gelo *et al.*, 2008; Mengshoel, 2012; Hesse-Biber, 2015; Shneerson and Gale,

2015). This pragmatic approach would use a mix of methods from both quantitative and qualitative paradigms within one study. A strength of this is that it enables different interpretations of results to be drawn, compared to those where one methodology is used (Burt, 2015). It also allows for complex factors to be investigated or for multiple viewpoints to be obtained, which might be difficult to do using just a quantitative or a qualitative approach (Shneerson and Gale, 2015). However, a mixed methods approach should only be employed where it fits with the purpose and aim of the study (Burt, 2015).

While mixed methods could have been adopted for this research (qualitative and survey methods) I wanted to obtain deep rich data about experiences, rather than risk obtaining superficial data through inadequate engagement with participants and testing the qualitative data collected through a survey.

During this research I wanted to explore the range of dietitians' experiences of being involved in decisions about ANH during their clinical practice. I wanted this to be an exploration of real life, not of hypothetical experiences. So from an ontological viewpoint, I believed that dietitians' lived experiences about decision-making will vary from person to person, and there will be more than one experience, so no one truth will be revealed. I also believed that the experiences will vary from context to context. One person may have one experience in one context, but the same person may have a different experience in a different context. For

example, where a dietitian was known to a team they may have one type of experience, but it may differ if the same dietitian is covering for a colleague and is not known to the team. Therefore, I needed to understand these multiple factors and contexts to enable me to understand the multiple realities of lived experience.

For this research to capture the complexity of the experience of decision-making, and to address the research question, it is likely that a qualitative methodology would be the most appropriate to use. Qualitative research is useful to answer questions such as these that are likely to have complex social and behavioural aspects to them (Shneerson and Gale, 2015).

Qualitative research is difficult to define concisely as it has developed over time and incorporates many facets and approaches; however, briefly it aims to provide an in-depth understanding of people's experiences of the world and how they make sense of the world (Merriam, 2014; Ormston *et al.*, 2014). There are many different qualitative approaches; indeed, Merriam (2014:7) describes the 'rich array of choices' for conducting qualitative research, therefore considering the objectives of this research will help to guide the best qualitative methodology for this research. They were:

- To explore dietitians' perceptions of their role in decision-making about ANH.
- To explore how different contexts influence dietitians' experiences of decision-making about ANH.

To understand the experience of dietitians, a research paradigm was needed which adopted an interpretive rather than a positivist epistemological position. I needed to reveal multiple realities of the meaning of the lived experience through the knowledge obtained during the data collection and data analysis. The data needed to be understood in order to fully explore the objectives of this research; that is, to reveal the embedded experiences, to uncover what is normally hidden or tacit, in order to understand how things are rather than how things appear to be. I needed to develop a partnership with the participants to reveal their experiences through questioning, and probing, and by encouraging the dietitians to reflect. For me to interpret and construct their lived experience, I needed to read between the lines of what the dietitians told me. A reflective, questioning and probing approach was needed for the data collection phase to allow new knowledge to be constructed and for rich interactions between my participants and myself as researcher.

As this was exploring experience and there were multiple realities of experience, a qualitative approach needed to be adopted. The next step was to consider different qualitative methodologies as discussed below.

4.3 Qualitative Methodology

Cresswell (1998) suggests that qualitative research allows an understanding of human or social problems through the views of participants. It aims to illuminate people's understanding and interpretation of their everyday life experiences and investigate the meaning people

attach to these experiences (Pope and Mays, 2000). Ormston *et al.* (2014) advocate a pragmatic approach to adopt the best methodology and methods to fit with the research question. However, to do this, the major qualitative approaches need to be considered.

There are many different types of qualitative approaches, although Creswell (1998) identifies the five major approaches as grounded theory, ethnography, case study, biography, and phenomenology. To consider which was most appropriate for this study, I followed McCaslin and Scott's (2003) advice to 'think backward' and consider what my findings might be in order to inform the methodology. However, I also needed to be mindful of pragmatic issues such as time.

Grounded theory is a methodology which aims to develop a theory to explain a phenomenon of interest which can then be tested (Strauss and Corbin, 1994). Savin-Baden and Howell Major (2013) suggest that researchers adopt a grounded theory approach with the hope of generating a theory by exploring relationships in incidents reported during the data collection. Data is commonly collected via observation, field notes, and interviews, and a constant comparative approach is used by which data is analysed and conclusions are drawn, which are then refined by the collection of more data (Willig, 2013). While grounded theory could be used to explore decision-making, I wanted to focus on the *experience* of decision-making; therefore grounded theory might not be the best approach to use for this research.

Ethnography aims to describe a culture or social group in order to understand the people in that group or culture (Harris *et al.*, 2009; Savin-Baden and Howell Major, 2013). It can be used to explore the lived experiences of a group (Savin-Baden and Howell Major, 2013), so could have been used as the underpinning methodology for this research. However, a key feature of ethnography is the extended and intense fieldwork undertaken to understand the group (Finlay and Ballinger, 2006). For this research the pragmatic reasons of time, part-time study, and the range of locations in which dietitians work meant that this would be impractical, therefore this methodology was not used.

A case study is an investigation of a 'bounded system' (McCaslin and Scott, 2003), with the case being the situation or instance that the researchers intend to study (Savin-Baden and Howell Major, 2013). This might range from an individual to a whole organisation or communities (Harris *et al.*, 2009); for example, an individual, an education programme, a care process, or an organisation (Baxter and Jack, 2008). Case studies can be used to address questions of 'how' and 'why' (Yin, 1994), and can reveal contextual features related to the phenomenon of interest (Baxter and Jack, 2008). Case studies commonly use data in the form of documents, records, interviews, and observation, with these multiple sources contributing to the understanding of the phenomenon (Baxter and Jack, 2008). While contextual features will have an influence on decisions about ANH, it was the *experience* of involvement which was the key phenomenon of interest for my research, therefore a case study approach

might not best illuminate the experiences of dietitians' involvement in decisions about ANH.

Biography, or biographical research, aims to understand changes in outlook and experiences of individuals in order to identify what is important to them (Roberts, 2002). It concentrates on the accounts of an individual (McCaslin and Scott, 2003; Bornat, 2008) to interpret changes in their past, present, and future life experiences (Roberts, 2002; Bornat, 2008). While experiences are key to this research methodology, as it focuses on the study of a single individual it was considered not suitable for this research.

Phenomenology explores the lived experience of participants' (McCaslin and Scott, 2003), and as the experience of dietitians was central to the research question, phenomenology was identified as the most appropriate methodology for this research. The different types of phenomenology and a justification for the use of interpretive phenomenology derived from the work of Heidegger will now be explored.

4.3.1 Phenomenology

The philosophy of phenomenology

When philosophers write about phenomenology, they are not describing a research methodology but a way of exploring abstract phenomena like consciousness and being (Moran, 1999; Caelli, 2000). I am not a philosopher: I have adopted the practice of phenomenology as a methodology for inquiry. However, consideration of the philosophy of

phenomenology is needed to map how it has developed from a philosophy to a methodology for research.

Edmund Husserl was the founder of phenomenology as a movement, which aimed to discuss a theory of knowledge (Moran, 1999). It is epistemological in nature, as it aims to enable experiences to be known (Taylor, 2013). Husserl believed that a specific approach was needed because individuals do not critically reflect on their experiences (Lopez and Willis, 2004). This approach aims to find the common features or 'universal essences' of the experience (Lopez and Willis, 2004) and to report these without making assumptions (Bradbury-Jones *et al.*, 2009). To reduce the influence of the researcher assumptions, Husserl argued for bracketing or suspension or reduction of previous views in order to develop a pure phenomenological understanding of the phenomena of interest (Moran, 1999). For Husserl bracketing was derived from the mathematics term, where brackets allow for one aspect of an equation to be separated from the rest so it can be concentrated upon (Hamill and Sinclair, 2010). The notion of bracketing was problematic for many of Husserl's students, not seeing the value of it or whether it was possible to undertake (Moran, 1999). Therefore, Husserl's phenomenology was further developed by one of his students, Heidegger, into hermeneutic or interpretive phenomenology. Heidegger's phenomenology did not include bracketing because he believed that we have to understand the world in which the phenomenon takes place or 'comes alive' (Heidegger, 1967:96),

that we have to be a being which is 'Being-in-the-world' to understand the phenomenon of interest (Heidegger, 1967:78).

Interpretive phenomenology aims to understand the experience or the nature of Being, so is ontological in nature (Moran, 1999; Taylor, 2013). In Heidegger's work *Being and Time*, he defines what he means by phenomenon by going back to the Greek roots of the word. He said it is derived from the verb meaning 'to show itself', or 'wherein something can become manifest, visible in itself' (Heidegger, 1967:51). Therefore, phenomena are what 'can be brought to light'. It is 'that which shows itself as Being and as a structure of Being' (Heidegger, 1967:63). Heidegger notes the difference but also the interconnectedness of phenomenon which shows itself and phenomenon as semblance. He stated, 'Only when the meaning of something is such that it makes a pretension to showing itself – that is, of being phenomenon- *can* it show itself as something which it is not; only then can it 'merely look like so and so' ' (Heidegger, 1967:51). Heidegger also referred to 'idle talk' (Heidegger, 1967:296), which is when a second-hand experience is described which can dilute an experience (Cerbone, 2008). Therefore, Heidegger suggests that normal practice or 'average *everydayness*' [original emphasis] needed to be explored in order for phenomenon to show themselves (Heidegger, 1967:30).

The meaning of Being was central for Heidegger, and he suggested that 'to work out the question of Being adequately, we must make an

entity...transparent in his [sic] own Being' (Heidegger, 1967:27). To do this, Heidegger used the term Da-sein or Dasein. Dasein can be translated as a verb to mean 'to exist' or 'to be there'. However, it is also a noun, which means 'presence', 'existence', or 'life' (Cerbone, 2008). Da-sein (hyphenated) is also commonly stated as meaning 'Being-there' (Macquarrie and Robinson, 1967; Cerbone, 2008). Dasein 'is a being whose being is an issue for it [and also] a being who has an understanding of being' (Cerbone, 2008:5). '*Understanding of Being is itself a definite characteristic of Dasein's Being*' [original emphasis] (Heidegger, 1967:32). To explore Dasein, it is necessary to look at a range of things, as it is unlikely that there is just one useful thing (Cerbone, 2008). It is also important to look at how these are related or connected. 'The relational character of useful things helps to convey this unified character of being-in-the-world' (Cerbone, 2008:41). This can be summarised by looking at:

1. 'Things' (or ready-to-hand or equipment or signs) as useful 'things'
2. These things need to be related to the task they are involved with
3. We need to consider how these things relate to each other
4. We need to consider these referential relationships, as it is these which make the thing what it is. (After Cerbone, (2008))

Phenomenology as a methodology

Phenomenology has developed over the years of it being used as a research methodology as it is 'dynamic and constantly developing', and can be 'fluid and creative' (Finlay, 2009:477). Although there is no consistent definition of phenomenology (Johnson, 2000), as a

methodology it is generally accepted to be the study of phenomena and human experience (van Manen, 1990; Baker *et al.*, 1992). That is, it explores lived experiences, through emotions, attitudes, and thoughts, and tries to give meaning to these experiences (Polit and Tanto Beck, 2008; Reeves *et al.*, 2008; Harris *et al.*, 2009).

There are many different styles of phenomenology (Norlyk and Harder, 2010). In fact, it has been suggested that there are as many different styles as there are phenomenologists (Finlay, 2009). However, broadly speaking, the two main types of phenomenology are descriptive and interpretive, which developed from the work of Husserl and Heidegger respectively (Lopez and Willis, 2004; Polit and Tanto Beck, 2008). It is important to articulate which type of phenomenology is being used as a methodology to ensure that the methods are congruent with this approach. Lopez and Willis (2004) also argue that this is important because the research findings generated will differ depending on the type of phenomenology used. I will now briefly consider descriptive and interpretive phenomenology and justify the decision to use interpretive phenomenology in this research.

Descriptive phenomenology

Descriptive phenomenology focuses on the human experience and aims to find the common features or 'universal essences' of the experience (Lopez and Willis, 2004) and to report these without making assumptions (Bradbury-Jones *et al.*, 2009). Therefore, it has been described as the

unbiased study of things as they appear (Dowling, 2007) and aims to describe experiences (McConnell-Henry *et al.*, 2009). Bracketing is included in descriptive phenomenology as a process of reducing bias from the researcher's preconceived ideas (Lopez and Willis, 2004; Polit and Tanto Beck, 2008). Bracketing is where the researcher's previous knowledge, beliefs, and preconceptions are identified and stated, and the researcher then attempts to put them to one side in order to be able to concentrate on the phenomenon without these influences (Gearing, 2004). It is hoped that this bracketing provides a greater 'transparency' to the data collection and analysis process (Lopez and Willis, 2004; Polit and Tanto Beck, 2008).

If bracketing can or should occur in research has been debated in the literature. Tuohy *et al.* (2013) questioned if bracketing was possible; they wondered if researchers really can put aside everything that has influenced them on a research topic. Clancy (2007) believed that the authenticity of research can be compromised if researchers do not acknowledge their own experience of a topic. She also believed that relationships between the participants and researcher might be negatively affected if the participants knew the professional background of a researcher but the researcher had bracketed this role and knowledge during the interview.

I considered whether it was possible for me to adequately bracket my views and experiences and concluded that I could not. I am an

experienced dietitian who would be talking to other dietitians about their experiences, so I did not think I could truly put my experiences to one side and not have these influence the data collection or data analysis. I also wanted to reveal what is normally hidden in experiences, so I wanted to draw upon my clinical experience as a dietitian. I also wished to *understand* dietitians' experiences of involvement in decision-making and not just describe it, which descriptive phenomenology would not allow me to do. So for these reasons I decided not to use this approach for this research.

Interpretive phenomenology

Interpretive phenomenology (sometimes called hermeneutic phenomenology) aims to interpret, understand, and show differences in the human experience instead of just describing it (Benner, 1994; Koch, 1999). It hopes to clarify what is normally hidden in the experience, and focuses on the experience rather than what individuals consciously know, as with descriptive phenomenology (Lopez and Willis, 2004). It also aims to uncover commonalities and differences (Benner, 1994) and accepts that the experience people have is situated in their world (Crist and Tanner, 2003), and everyday life (Draucker, 1999). Holloway and Wheeler (2013) note that reflection is key in order to uncover this experience. While many researchers have used interpretive phenomenology as a methodology for enquiry, the work of van Manen has been recommended as an applied approach to interpretive phenomenology (Taylor, 2013) so this was explored further as a methodology to guide this research.

Van Manen's work is based on hermeneutic phenomenology (Earle, 2010) as he believed that lived experience had to include interpretation of phenomena (van Manen, 1990). Van Manen's personal research using phenomenology is related to pedagogy (van Manen, 1990); however, the work of van Manen has been used to guide health-related research to explore the lived experience of patients, families, and healthcare professionals (Maggs-Rapport, 2001; Earle, 2010). Van Manen's writings offer guidance on the use of interpretive phenomenology as a methodology for inquiry rather than an abstract philosophy (Earle, 2010) and so he has developed phenomenology as a methodology (Dowling, 2007).

Van Manen (1990) suggests that the researcher needs to concentrate on the phenomenon as a human experience, in this case the *experience* of dietitians. He also suggests that in hermeneutic interviews the researcher and the participant become co-investigators (van Manen, 1990). So the reflection which occurs in the interviews is collaborative as the participants need to reconstruct and reflect upon their experience (Seidman, 2006). However, as it is their experience, skill is needed on the part of the researcher to listen and not judge (Lindseth and Norberg, 2004). (See section 4.9 on reflexivity for more detail.)

Bracketing does not normally occur in interpretive phenomenology (Lopez and Willis, 2004; Bradbury-Jones *et al.*, 2009). This is because there is a co-construction of the experience between participants and researcher (de

Witt *et al.*, 2010) where the researcher is active in the interpretive process (Draucker, 1999). Van Manen supports the lack of bracketing but stresses that researchers need to be aware of their pre-suppositions and to question and reflect upon them during the research process (van Manen, 1990). Without this there is a risk that the researcher will just look for evidence to support their current position, and hidden experiences may not be revealed, meaning that there is the risk that the researchers' interpretation could be biased (Parse, 2001). It is important to see what influenced the researcher in the decisions they made and in the interpretation of the data (Koch, 1996; Draucker, 1999), and how the researchers' position and experiences contributed to their interpretation and views (Draucker, 1999). My influences are discussed in section 4.9 on reflexivity and positionality.

4.4 Methods

Given that interpretive phenomenology was chosen as the most suitable methodology to explore the research question, it was important to consider the most suitable methods to collect the data to ensure congruence between methodology and methods. I needed to adopt methods which would allow me to enable dietitians to uncover and reveal their everyday clinical experiences of decision-making about ANH. However, there is a challenge to this as participants may not be aware of everyday normal things until things go wrong (Heidegger, 1967; Cerbone, 2008). Larkin *et al.* (2006) suggest that for some skilled professionals they do not actively think about their practice until things are out of the ordinary (Larkin *et al.*,

2006). Therefore, taking these factors into account, the options for data collection will now be discussed.

4.4.1 Options for data collection methods

When considering how to collect the data for this research, I was mindful of the issue of method slurring. Method slurring is when the methods chosen to conduct the research do not align with the philosophical underpinning of research methodology (Baker *et al.*, 1992), which might affect the rigour of the research (Wimpenny and Gass, 2000; Johnson *et al.*, 2001). To do this I needed to consider what methods would be suitable for interpretative phenomenology.

Exploring appropriate methods to use in this research was challenging as the literature is full of conflict in this area (Caelli, 2001); for example, if observation is suitable phenomenological research, some suggest it is suitable while others suggest it does not enable deep reflective data to be collected (Holloway and Wheeler, 2013; Merriam, 2014). The types of methods commonly used in phenomenological research include in-depth interviews and analysis of personal documents such as diaries and critical incidents (Standing, 2009). However, any data which would help to answer the research question would inform the methods to be chosen for this research (Newell and Burnard, 2006), therefore other methods of data collection were also explored. Using more than one method may be advantageous for method triangulation, which can enhance the rigour of a

study (Begley, 1996; Long and Johnson, 2000). (For a detailed discussion of quality see section 9.3.)

Focus groups

Focus groups, which Mack *et al.* (2005:51) described as when 'one or two researchers and several participants meet in a group to discuss a given research topic', were considered for data collection. Advantages include the ability to collect a lot of data in a short period of time and that ideas can be developed as they are 'bounced off' other participants through interaction with each other. However, they are not recommended if sensitive topics are being discussed (Krueger and Casey, 2000; Mack *et al.*, 2005), and, as shown in the literature review, discussions regarding decision-making in ANH can be emotive. Personal views and values will influence the experience, and participants may not feel comfortable talking about their feelings and personal beliefs within a focus group. Bradbury-Jones *et al.* (2009) note that a disadvantage of focus groups includes the risk of group contamination, with people's views being influenced by others in the group. Because of this, Webb and Kevern (2001) suggest that focus groups are not compatible with phenomenology as the participants need to reflect on their experience in an uncontaminated way. It has also been suggested that focus groups should not be used if other methods can produce better quality data (Krueger and Casey, 2000). Because of these multiple reasons, focus groups were not used to collect data in this study.

Observation of practice

Participant observation has its roots in ethnographic research (Mack *et al.*, 2005) and involves observing participants in the setting in which the phenomena of interest occur (Merriam, 2014). It allows for interactions between key people and for the environment to be observed in context: so for this research, observing interactions between dietitians and other team members, and dietitians and patients perhaps in their own home, during decision-making. When used with focus groups or interviews, participant observation may result in more informed discussions (Harris *et al.*, 2009).

Merriam (2014) suggests that observation is a suitable technique when the situation can be observed first hand. However, in this research I wanted to uncover what is normally hidden in the experience for dietitians, so observation would not be the best method for this. While observation could be followed up with an interview to enable reflection, it was deemed unsuitable for the following reasons. Observations would be needed in many different settings, at times when involvement in decisions about ANH are made. Depending on the clinical area, this may not be every day, so it would prove difficult to select a time when it would be hoped that I would be able to observe these situations. As I am familiar with the environment in which these decisions occur through my personal clinical practice and when visiting students on placement, I am also mindful that often the interactions and discussions occur on the phone, when observation of all parties is impossible. Therefore, observation was not used as a method to collect data in this study.

Written accounts

Written accounts, such as diaries and critical incidents, are a common form of data collection within phenomenological research (Standing, 2009).

Diaries for research are solicited in advance and can be structured or unstructured (Ross *et al.*, 1994; Jacelon and Imperio, 2005). Structured diaries use a series of prompt questions to explore difficult situations.

Rather than diaries van Manen (1990:63) refers to 'protocol writing' or 'lived experience descriptions' where participants are asked to write their experiences down by focusing on a specific event. Van Manen (1990) suggests that this reflective account of an incident enables the participant to reflect upon their experiences, which can result in a better understanding of these experiences.

Using written accounts as a sole data source can be problematic for the following reasons. Written accounts can lack the subtlety of the spoken word (Jacelon and Imperio, 2005). Unstructured diaries require a lot of motivation for the participants to complete (Ross *et al.*, 1994) so they may not be completed, whereas structured diaries may lead to bias as the focus of the diary is guided by the researcher not the participant (Clayton and Thorne, 2000). Written accounts may contain inaccuracies (Zimmerman and Wieder, 1977), and there is a risk of the participant reporting what they think the researcher wants to hear (Landeem *et al.*, 1995).

Zimmerman and Wieder (1977) describe the development of a 'diary-interview method' which aims to address some of these limitations. The process involves interviewing someone after a written account has been kept. The diary is reviewed before the interview and is used for a basis of question formation. This enables clarification, it can help to reduce making assumptions in meaning, and can lead to deeper exploration of the issues identified (Begley, 1996).

Diaries require a lot of effort on the part of the participant, but a reflective account of a clinical event, which is of phenomenological value, could be incorporated into an interview and so is congruent with interpretive phenomenology. This will be further discussed in the next section.

Interviews

Mack *et al.* (2005) suggest that interviews are one of the most commonly used methods in qualitative research and may be structured, unstructured or semi-structured (Merriam, 2014). Structured interviews have a set of questions or topics to guide the interview, semi-structured interviews may have a topic guide to ensure that aspects are not missed, and unstructured interviews have a grand tour question to begin the interview with open questions to continue the interview (that is, a process of funnelling to narrower topics). Probing for further thoughts and reflection may be needed as the interview proceeds (Paterson, 2005). Unstructured interviews are used when little is known about a topic and when interview questions for further study need to be developed (Merriam, 2014). The

advantages of using in-depth interviews for data collection are that a richness of data can be obtained, especially if a less structured approach is used (Ajjawi and Higgs, 2007). For example, van der Riet *et al.* (2009) found that in their study the doctors interviewed tended to be more expansive in their responses compared to the nurses who attended focus groups. Interviews are also helpful to see the connections that participants make when they are discussing their experience (Mack *et al.*, 2005).

In-depth semi-structured interviews are congruent with an interpretive phenomenological approach as they collect information about the experience and facilitate participant reflection. Reflection can be further developed if more than one interview is conducted (van Manen, 1990). Indeed, in Lindseth *et al.*'s (1994) research they found that when the same participants were interviewed again a new story developed with more of a personal view given rather than the previously reported professional view. Repeated interviews are common in interpretive phenomenology (Crist and Tanner, 2003).

There are challenges associated with using interviews within an interpretative phenomenological approach. It is important for the researcher to be reflexive so they do not just find what they thought they would find. Crotty (1996) stated that 'it is only too easy for researchers to structure the data-gathering process in ways that virtually guarantee them the data they are after' (Crotty, 1996:20). Therefore, the researchers' pre-

understandings, or preconceived ideas about the research need to be challenged. This can be achieved by checking their preconceived ideas during the interviews to enable them to be confirmed or rejected, and by deep reflection as recommended by Paterson and Higgs (2005). Van Manen (1990) acknowledges the difficulty of keeping questions open and focused on the phenomenon in question. To aid this, Crotty recommended researchers to use phenomenological questions such as, 'What is it like?' or, 'What does it mean for you?' (Crotty, 1996), and Seidman (2006:88) recommends questions such as, 'What happened?' or, 'What was that experience like?'

4.5 Sample size

Determining the appropriate sample size in qualitative research is an area of debate (Morse, 1993; Seidman, 2006; Trotter, 2012; O'Reilly and Parker, 2013). The number of participants needs to be large enough to obtain a rich sample to be able to address the research question (O'Reilly and Parker, 2013), but not so large that the amount of data collected cannot be coped with (Morse, 1993). Seidman (2006:55) considers 'sufficiency' in his debate about sample size; that there are enough participants to reflect the range of people who normally make up that population. If a researcher aimed to explore the views of experts, then a smaller sample size may be sufficient, as there are likely to be a smaller number of experts compared to non-experts and because there *may* be less variation of views among experts (Trotter, 2012). However, if a researcher aims to hear a range of

experiences from a range of participants, then a larger sample may be required.

Data saturation or redundancy may also influence sample size. Data saturation is when interviews continue until all questions have been thoroughly explored and no new themes are heard, while redundancy is when concepts are repeated a number of times in different interviews without new themes emerging (Trotter, 2012). It has been suggested that data saturation or redundancy indicates that enough data has been collected (Morse, 1995; Seidman, 2006). However, O'Reilly and Parker (2013) contest the concept of data saturation, as it is a term from grounded theory which is being applied to other methodological approaches without adequate justification. Indeed, it could be argued that data saturation is unlikely to be obtained in methodologies such as interpretive phenomenological research, as lived experiences will vary and there is unlikely to be one reality of experience.

However, given these debates, guidance on sample size is still welcome. Within phenomenological research, Creswell (1998) recommends up to 10 participants, Ebbesen and Pedderson (2007) suggest a sample size of 15 ± 10 , and Ajjawi and Higgs (2007) state that they obtained 'data saturation' from a sample size of 12 physiotherapists of varying years of experience. So a sample size of anything between five and 25 participants may be adequate.

4.6 Field work

4.6.1 Interviews and reflective account

The phenomenon in this research was the experience of being involved in decisions related to the provision of ANH. So exploring thoughts and feelings to get to the phenomena through the accounts of this lived experience took the form of discussions around everyday provision of feeding and decision-making.

I used two in-depth, semi-structured interviews for the major part of my data collection, approximately eight weeks apart. The first interview began by gaining demographic information and some information about personal views, beliefs, culture, and values, as these factors may influence their experiences. I then went on to ask about normal, everyday practice.

Heidegger referred to this as 'average *everydayness*' [original emphasis] (Heidegger, 1967:30). The interview then went on to ask about difficult situations and conflict. The interviews ended with a discussion about a single hypothetical case, as I was concerned that the interviews would not provide rich data. However, during the data analysis it became clear that discussion about a hypothetical case was not needed, as rich data relating to their first-hand experiences was obtained. Therefore, only data about *their* experience was included in the data analysis, as it was speculation about what they would do, or what Heidegger referred to as 'idle talk' (Heidegger, 1967:296). However, for some participants the case study led them to talk about similar real cases they had experienced, so when this happened, the data was included. As suggested by Wimpenny and Gass

(2000) a topic guide (see Appendix 2) was used to remind me about certain issues that I wished to explore, but it was not used rigidly as I wanted to allow some flexibility for me to be responsive to what the participants said. The interview topic guide was piloted as recommended by Clancy (2007) by interviewing two dietetic colleagues and it was suitable to explore their experiences. The pilot also enabled me to practise my interview skills.

To allow for reflection and member checking, the process which allows participants to check the accuracy of their transcript or to check the findings of a study (Long and Johnson, 2000; Kuper *et al.*, 2008), each participant was provided with a full transcript of both of their interviews to enable them to check that they were an accurate reflection of the interviews, and also to check that they were happy for their words to be used in my reporting of the research. They were given two weeks to do this. The transcript of the first interview was provided to the participants before the second interview.

I read over the transcript of the first interview in preparation for the second. The focus of the second interview was a clinical event which occurred between the two interviews. I had considered calling this a critical incident, but decided against it because there was the risk that the participants may not have experienced what they felt was a critical incident in the time frame, a problematic issue encountered by others (Reed, 1994). Therefore, I used van Manen's term 'reflective account' (van Manen, 1990:73). By

asking participants to write about a particular incident as the focus of their experience, it was hoped it would allow for deep reflection and so a better understanding of their experience (van Manen, 1990). The participants were asked to reflect on a clinical case and were given prompt questions to answer (see Appendix 3). The questions were piloted with dietetic colleagues to ensure that the questions were clear and specific. Larkin *et al.* (2006) suggested that skilled professionals may act tacitly, without thinking, so by asking the participants to reflect and break their actions down, it would allow for deep reflection of their experiences, which is of phenomenological value (van Manen, 1990). All the participants sent me their reflective account before the second interview. This allowed me to clarify any points I was unsure about, helped me not to make assumptions about meaning, and so aided deeper exploration of the issues (Begley, 1996). Discussing the reflective account with the participant also provided member checking (Clayton and Thorne, 2000) and so method triangulation (Begley, 1996). Both of these enhance the rigour of this research.

During the interviews I ensured that my pre-understandings or assumptions did not guide the interview by trying to ensure that the interview developed in as spontaneous a way as possible with a few open questions, and then only using prompts for clarification and to encourage the participant to continue talking. During the interviews I was careful not to give participants 'the right answer' even if requested and to not judge answers as recommended by Parse (2001), which may have inhibited discussion. I encouraged a reflective phenomenological interview by

asking what the experience was *like* and how they *felt*. I tried to obtain details of the experience from them before gaining opinions about the experience. I took notes on any points I wished to return to, so as not to interrupt the participant or the flow of discussion. I used active listening skills such as reflecting and paraphrasing to check my understanding. I was also mindful to concentrate on their experience and not mine or the experience of other participants as suggested by Seidman (2006).

For the convenience of the participants, and to ensure that they were in an environment they were comfortable with, the interviews were conducted in a private, quiet, and convenient place for the participants. This was either the participant's home or a quiet, private room at Coventry University. The first interviews lasted on average 1 hour 24 minutes (range 57 minutes 12 seconds to 1 hour 58 minutes 58 seconds), the second interviews lasted on average 51 minutes (range 35 minutes 12 seconds to 1 hour 19 minutes 17 seconds). This provided a total of 36 hours 3 minutes 59 seconds of recorded interview time.

4.6.2 Field notes

After the interviews I recorded field notes of my observations and thoughts on a standard form as inspired by Polit and Tanto Beck (2008) and Silverman (2005) (see Appendix 4). The form contained four distinct sections:

1) Observation notes. In this section I recorded information about the setting, the participant, and other relevant details. As recommended by

Begley (1996), I included comments on non-verbal communication in observational notes. However, I also commented on non-verbal communication during the interviews, to try to understand any additional meanings rather than making assumptions and to encourage deep reflective interviews.

2) Methodological notes, in which I reflected on the interviews.

3) Theoretical notes, which allowed me to begin to record what I felt might be going on with the research.

4) Personal notes, which included my own feelings about the interview and an opportunity for me to challenge previous assumptions.

The field notes contributed to my reflexivity and were used for method triangulation (Cutcliffe and McKenna, 2004). They were used during the data analysis to enable me to relive the interview, to reflect on what I felt was the meaning of the experience, and prompt me to question my pre-understandings in an attempt to enhance rigour.

4.6.3 Participants

As phenomenology explores the lived experience, I needed to recruit participants with the experience of being involved in decision-making related to ANH. I aimed to recruit dietitians who were able to give a rich description of their experiences. I also wanted to hear from dietitians who worked in a range of clinical settings and had varied levels of experience as these are likely to influence experiences (Jansson *et al.*, 1995; Langdon *et al.*, 2002). Therefore, I aimed to recruit staff with a range of

years of experience. Acute care dietitians who work in hospital may have different experiences of decision-making compared to community dietitians, especially as many patients who receive ANH at home start it in hospital. Therefore, I hoped to recruit from a range of settings, that is, community and acute hospital-based staff. However, while I wanted to obtain multiple perspectives, I was mindful that I was not able, or indeed aiming, to produce a sample which was representative of the larger dietetic population.

4.6.4 Recruitment of participants

There are a number of sampling options which could have been adopted in this research; in fact Onwuegbuzie and Leech (2007) outline 24 different options for use in qualitative research. The purpose of sampling is to obtain a rich sample in order to be able to address the research question (O'Reilly and Parker, 2013). In this research purposive sampling was used. Purposive sampling is when participants are sampled to take part in the research because they will be able to provide data which is detailed and appropriate for the research (Oliver, 2006). The criteria for inclusion in this research were being a registered dietitian who had current clinical experience of treating patients requiring ANH. The purposive sample could have been stratified by age, experience, or workplace. This would have ensured that there would be participants from a range of settings or with a range of clinical experience. Ideally, a stratified sample should represent the wider population they were sampled from, thus enhancing the generalisability of the research. However, for this to occur, demographic

information about the wider population is needed, for example, the average years of experience in clinical practice and the numbers of dietitians working in different settings. I did not know this information, although it might have been available from the Health and Care Professions Council.

The West Midlands branch of the British Dietetic Association was used to recruit participants. This branch was used for a number of pragmatic reasons. Dietitians who work in the West Midlands were likely to live in or close to this area, so they would (hopefully) be geographically close, thus helping with travelling time for data collection. All dietitians need to be registered with the Health and Care Professions Council, but the Health and Care Professions Council does not keep regional lists. However, the majority of dietitians are also members of the British Dietetic Association, so this route proved to be a convenient way to recruit local dietitians. A limitation of this was that these potential participants might have been known to me; this was an issue I considered in section 4.9 on reflexivity and positionality. I could have sampled from other branches, but this was considered impractical for data collection.

The chairperson of the West Midlands branch of the British Dietetic Association acted as a gatekeeper for recruitment. Gatekeepers have various roles which not only include granting access to participants from which a sample may be recruited (Wanat, 2008) but also protecting participants from unwanted attention and intrusion (Walker and Read,

2011). After ethical approval was obtained, the chairperson of the West Midlands Branch of the British Dietetic Association emailed an invitation for dietitians to take part in the research. The email included a brief outline of the study and my contact details for anyone interested to reply to (see Appendix 5). Responses to the first email were followed up by an emailed information sheet about the study and a request to arrange a time to phone to discuss the study in more detail (see Appendix 6).

The email invitation resulted in 22 replies. One participant was not interviewed because she had a management role with little current relevant clinical experience, so did not have recent lived experience of decision-making about ANH. Two participants responded to the initial email invitation but then failed to respond to emails after an information sheet about the research was sent. One participant withdrew before the first interview. One participant was due to go on maternity leave and was not able to complete all the data collection and so was not included in the research. One participant replied after completion of the data collection stage so was not included. Snowballing, the process of recruiting participants via recommendations from others, was used to recruit one participant. This dietitian was identified by other participants as someone who had a lot of experience of ANH. This resulted in 16 participants being recruited and completing the study.

Despite not using stratified sampling, (which in retrospect might have been appropriate to use to ensure a mix of experience and clinical areas), the

study participants had a range of experience, worked in a range of clinical areas, and have varied levels of seniority (see Table 1). If this had not been the case, I could have considered trying to recruit a more varied sample via snowballing. It was hoped that these varied participants would enable a range of experience to be revealed; however, this sample cannot be considered representative of the profession as a whole. All the participants recruited in this research were female. While dietetics is a female-dominated profession, with 95% of dietitians registered with the HCPC being female, 5% of the profession, male dietitians, are not represented in this research. Also, all the participants recruited worked in adult services, and dietitians who work in paediatric services are not represented. It must also be noted that the participants recruited for this research were self-selected. They may have volunteered to take part in the study because they had an interest in the topic area, so they are different to those who did not volunteer to take part. So caution is needed not to generalise the findings of the research to the whole of the profession of dietetics. (Generalisability will be discussed further in section 9.4.)

Table 1 - Details of participants

ID	Current main area of clinical work	Main location	Approximate years of experience	Band
1	Stroke, rehabilitation, and mental health	Hospital and community	2	5
2	Mental health, surgical, and stroke	Hospital	1	5
3	Home enteral feeding	Community	2	6
4	Home enteral feeding	Community	7	7
5	Liver and general medical wards	Hospital	1 ½	5
6	End-of-life – palliative care	Community	28	7
7	Gastroenterology and general medical wards	Hospital	1	5
8	Neurology and adults with learning disability	Community	22	6
9	Oncology	Hospital and outpatients	12	7
10	Oncology	Hospital	23	6
11	Stroke	Hospital	2 ½	6
12	Elderly care	Hospital	8	6
13	Nutrition support, ITU	Hospital	13	6
14	ENT and maxillofacial	Hospital	2	5
15	Critical care, nutrition team	Hospital	6	7
16	Nutrition support, ITU, and trauma	Hospital	8	7

4.7 Analysis

There is no one standard method for data analysis (Wilding and Whiteford, 2005) and many different approaches have been used in interpretative phenomenology (Draucker, 1999). I used the analysis method recommended by van Manen (1990) which involved reflecting on the meaning of the lived experience through the development of themes, and by writing, reflection, and rewriting.

4.7.1 Data management

The first part of the data analysis was data management. I first transcribed all the interviews verbatim, maintaining time gaps and emphasis on words so as not to lose any of the nuances of the interview, and then uploaded them into NVivo 9 (QSR International). The first and second interviews for each participant were uploaded together to form one interview data file for each participant. The interviews were analysed together because many participants began the second interview by saying that they had reflected on the first interview with colleagues, and this was explored with them in the second interview. I also revisited some of the issues discussed in the first interview, therefore the two interviews were linked. Full discussion of the participants' written reflective accounts occurred in the second interview, so they were not uploaded for further analysis. However, these reflective accounts could provide an additional data source which could be further analysed to reveal the types of clinical events the dietitians reflected upon. This would provide some extra context to further illuminate

the participants' experiences. This data could be analysed for future publications.

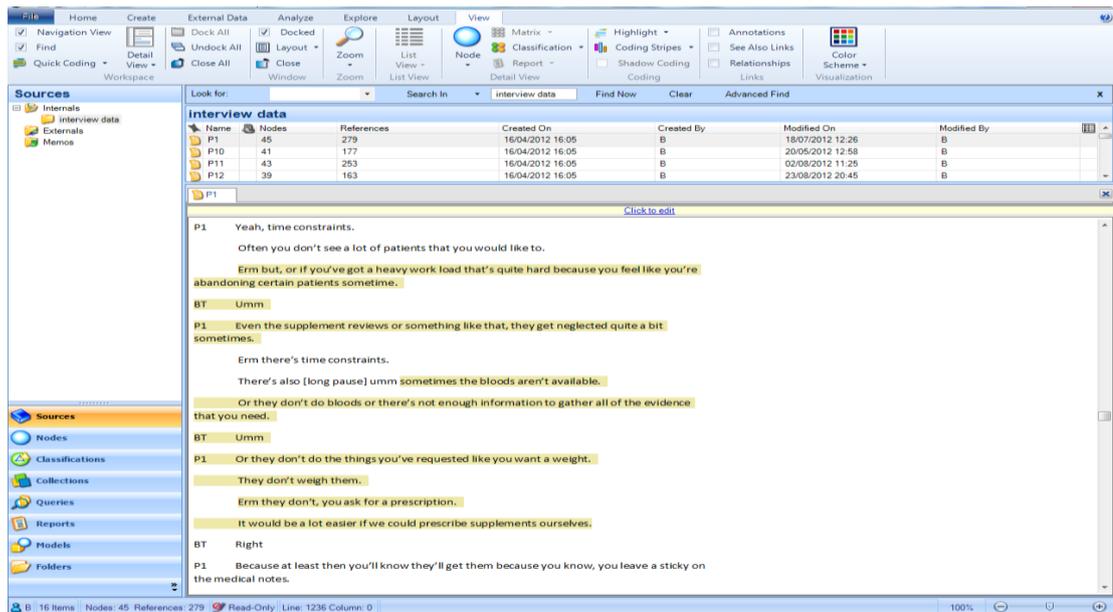
The field notes were read during the transcription to ensure that notes on non-verbal communication were included. After transcription I listened to the recordings while simultaneously checking the written record for accuracy. Finally, the transcripts were printed out for final checking of spelling and grammar as recommended by Seidman (2006). This allowed me to accurately transcribe the interviews and to become immersed in the data and the life-world of the participants.

4.7.2 Data analysis

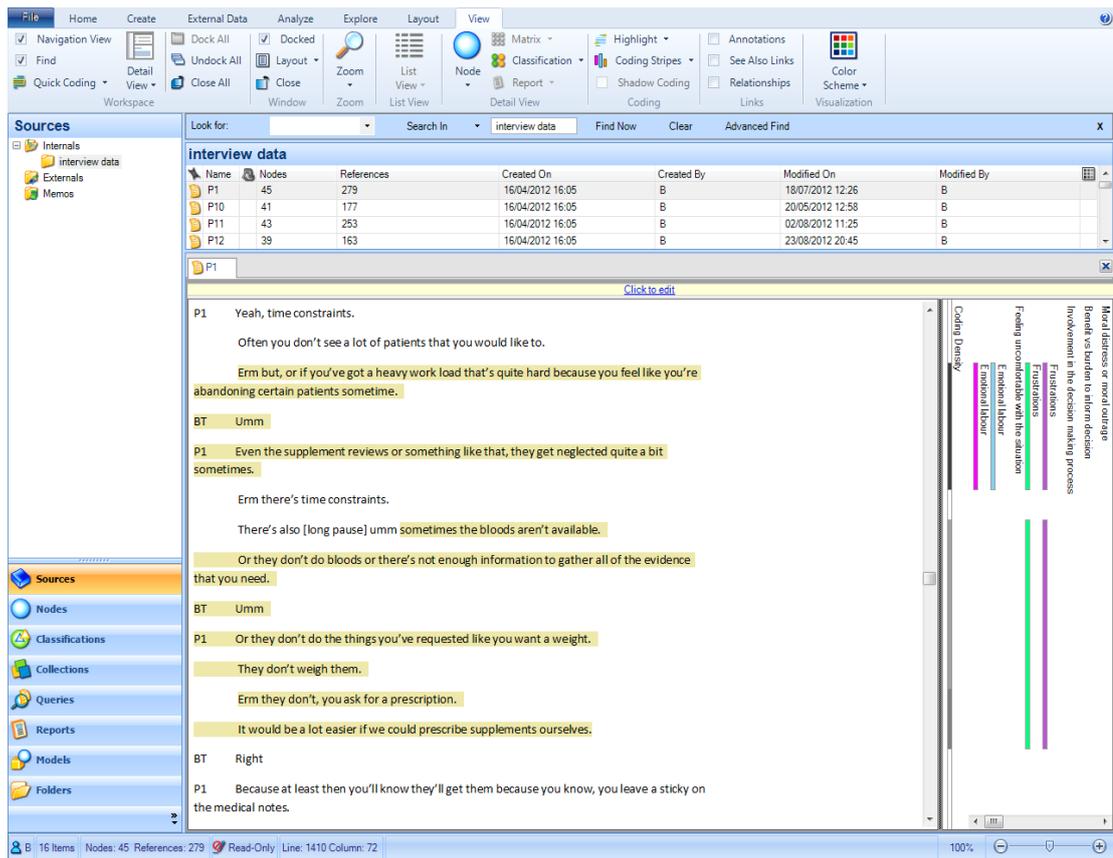
Once the data was transcribed, it then needed to be made sense of to reveal and understand the experience of being involved in decisions for dietitians. The following stages of thematic analysis were undertaken, as described by van Manen (1990).

Step 1

The first stage of data analysis was to reduce the size of the data without losing its rich meaning of the lived experience. I used a detailed or line by line approach, as described by van Manen (1990), in which every sentence or sentence cluster was examined and statements which were about decision-making or revealed a meaning of the experience were highlighted. These highlighted areas formed 'units of meaning' as illustrated below.



The highlighted 'units of meaning' were then coded to capture the essence of the highlighted data. This was repeated across the whole data set for all the interviews. To enable peer review, (when others with experience of qualitative research review the data and processes (Holloway and Wheeler, 2013)), my supervisors independently coded a proportion of two transcripts, and areas of disagreement were discussed. The screen shot below shows the highlighted units of meaning in the main box, with the codes assigned to that data in the box on the far right-hand side.



Step 2

The codes from all the transcripts were then grouped together with similar codes to form categories. Discussion with my supervisors facilitated my reflection on the categories to help with the interpretation of the meaning of the experiences captured in the codes and to ensure that meaning was not lost. The NVivo codes for the categories used are shown in the following table (Table 2).

Table 2 - NVivo Categories

Broad category area	Categories
Managed feelings	<ul style="list-style-type: none"> • Feeling weight on shoulders • Dignity • Are they telling us something? • Role of food and nutrition in caring • Is it right? • Burdens • Support • Feeling comfortable with the situation • Emotional labour • Feeling uncomfortable with the situation
Control	<ul style="list-style-type: none"> • Frustrations • Involvement in the decision-making process • Respect • Patient information giving • Powerlessness and lack of control • Feeling in control of the decision or situation • Conflict • Battles
Dietitian as expert	<ul style="list-style-type: none"> • Other healthcare professionals' views • Expert • Moral distress or moral outrage • Moral agency • Benefit vs burden to inform decision • Responsibility • Honesty and truth telling
The wider team, patient, and working issues	<ul style="list-style-type: none"> • Communication • Relationships • Team working • Policy and procedure • Expectations • Religion in decision-making

Step 3

The categories were then grouped together to form overarching themes, again taking care not to lose the meaning of the lived experience. An initial theme of 'emotions' was modified to 'managed feelings' as illustrated in Table 3 below.

Table 3 - Modification of the theme of emotion to a theme of managed feelings

Emotions	Managed feelings
<ul style="list-style-type: none">• Frustrations• Emotional labour• Letting someone die• Uncertain if doing right• Poor QoL• Are they telling us something?• Dignity• Feeling weight on shoulders• Feeling okay	<ul style="list-style-type: none">• Feeling weight on shoulders• Dignity• Are they telling us something?• Role of food and nutrition in caring• Is it right?• Burdens• Support• Feeling comfortable with the situation• Emotional labour• Feeling uncomfortable with the situation

Step 4

In this step I tried to capture and interpret the core meaning of the theme. This was done by writing about the theme with illustrative quotes from participants, then reflecting on this writing. The themes were then reviewed and revised repeatedly until a coherent picture of the lived experience was formed (Cohen *et al.*, 2000). During this stage decisions were made about whether a theme was essential to the experience being explored or whether it was incidental (van Manen, 1990; Earle, 2010).

Care was taken not to remove essential themes, so as to not change or lose the meaning of the experience. While time-consuming, the process of writing, reflecting, revising, and rewriting was key in order to capture the lived experience. This process has been described as the hermeneutic circle (Porterfield, 2009), or maybe more accurately as a spiral as it is not static and moves the analysis and understanding forward (Paterson, 2005; Debesay *et al.*, 2008). Thus the themes developed as shown in Table 4.

Table 4 Development of themes

First development of themes	<ul style="list-style-type: none"> • Frustrations • Communication • Dietitian as expert • Emotional response to situation • Fight for patients • Multi-disciplinary team decision-making • Power and hierarchy • Quality of life • Support from colleagues • Team working
Re-development of themes	<ul style="list-style-type: none"> • Burdens • Relationships • Frustrations • Moral agency • Emotional labour • Support • Moral distress or moral outrage • Patient empowerment • Involvement in the decision-making process • Powerlessness • Expert • Battles • Other healthcare professionals' views • Expectations • Role of food and nutrition in caring
Re-development of themes	<ul style="list-style-type: none"> • The wider team including the patient and working issues • Dietitian as expert • Managed feelings • Control

Re-development of themes	<ul style="list-style-type: none"> • The varied roles of dietitians in decision-making • Who has the power in decision-making related to ANH? • Dietitians and moral agency • Managing emotions in decision-making
Re-development of themes	<ul style="list-style-type: none"> • So much more than deciding on a feed • Wanting to be heard • The emotional roller coaster • Responding to the emotional lows
Final themes and subthemes	<ul style="list-style-type: none"> • So much more than deciding on a feed <ul style="list-style-type: none"> ○ Dietitian as expert ○ Dietitian as educator ○ Dietitian as advocate ○ Dietitian as technician • Wanting to be heard <ul style="list-style-type: none"> ○ Trying to be heard ○ Being known ○ Making a difference ○ Speaking up ○ Silenced • The emotional roller coaster <ul style="list-style-type: none"> ○ Proud to do a good job ○ Feeling angry ○ It's my fault ○ Don't show it ○ Keeping a distance ○ Becoming desensitised ○ Speaking out ○ Needing support

How some of the themes developed and were revised are more fully illustrated in Appendix 7.

4.8 Ethical considerations of performing this research

Rigorous conduct of research includes attention to the principles of ethical research as laid out in the declaration of Helsinki (World Medical Association, 2013), of which the overarching principle is the well-being of

the research participants. The Economic and Social Research Council (Economic and Social Research Council, 2015) also has a framework specifically related to social research which has six principles that I adhered to as outlined below.

Participation in this research was voluntary. The initial recruitment was conducted via email rather than face to face or via personal contacts, and there was no obligation for anyone to reply. The potential participants were not coerced or influenced in any way to take part. An information sheet was emailed before I met with any participants, so they could gain information about the study and decide whether they wished to take part before we met, so avoiding putting pressure on the possible participants.

Participants were treated with respect and dignity. In reporting the findings, I have been mindful to be respectful to the participants. This has included correcting any colloquial language (while being careful not to distort the data in anyway) so the participants are not represented as having poor language skills. I have also been mindful of Seidman's (2006) advice not to put anything in a final report that would not be said to the participant's face, as Jacobson *et al.* (2007) suggest, harms in qualitative research may occur in the interpretation and representation of the research.

Ethical research conduct includes considering the risks, burdens, and benefits for the participants (Economic and Social Research Council, 2015). While it is difficult to know the actual harm that may arise from a

piece of research such as this (Jacobson *et al.*, 2007), it was important to make my potential participants aware of any possible harms. These might have included possible distress if they re-lived difficult experiences. No participants became distressed during the interviews; this may have been because I was mindful of being sensitive when interviewing the participants. However, as expected in phenomenological interviews, which aim for deep reflection, some participants did reflect on some personal life events including bereavement, which may have been troublesome for them.

There was also a small risk that during the interviews, unsafe practice might have been disclosed. I decided that if a participant's practice appeared to pose a serious risk to patient safety then I had a duty to report it to the Health and Care Professions Council as a registered dietitian. Unsafe practice does give grounds for breaking confidentiality if it affects patient safety (McHaffie, 1996), as it is the Health and Care Professions Council's role to ensure that dietitians are able to do their job safely (Health Care Professions Council, 2009). While I made the participants aware of this, I also made it clear that I was a researcher, not their manager, and I was not assessing their fitness to practise but their experience of the phenomena. Serious unsafe practice was not disclosed by any of the participants.

Discussions of clinical practice might have led participants to become aware of gaps in their knowledge which might be concern for some (Caelli,

2001). However, engaging in the reflective process can lead to 'interpretive awareness' (Caelli, 2001:279) and reflecting on practice is a Health and Care Professions Council requirement for continued registration (Health Professions Council, 2011).

The burdens of taking part in this research included giving up their time and completing the reflective account. Overall, it is hoped that the risks and burdens of taking part were outweighed by the possible benefits.

Many participants stated at the end of the interviews that it had been a good reflective exercise for them. Reflection had been prompted after the first interview by talking to colleagues, completing the reflective account, and through discussion of the reflective account. Many felt that they did not normally have time to reflect deeply, but the interviews had made them reflect and many could see the value of it. The reflective account had the benefit of being suitable for evidence of continued professional development, which is a requirement for all healthcare professionals to engage in to stay registered with the Health Professions Council (Health Professions Council, 2011).

Information about the research was provided to the potential participants before meeting, and they were given time to read the information sheet and think about the information and any questions they might have. The information sheet outlined what was expected from them in terms of two interviews being conducted and the use of a reflective account.

Participants were assured that their confidentiality and anonymity would be maintained. Anonymity of the participants was especially important as dietetics is a small profession. Therefore, some small details of clinical roles were omitted, as not doing so could have led to some participants being identified. For example, three participants had unique roles within the West Midlands so any details of those roles could have identified them personally. These changes were noted in the transcripts sent to the participants for checking, to ensure that they were happy with the changes made. Care was taken not to change the meaning of what was said or to distort the data in any way.

Before and during transcription all audio files were kept on a university computer and were password protected, as were the transcripts and all participant details. Anonymity was also maintained by deleting the recordings of the interviews after the transcripts had been checked by the participants as it might have been possible to identify a participant from their voice. After the participants agreed that the transcripts were a true representation of what they had said, they were then given an ID number rather than their initials to further protect anonymity and maintain confidentiality. All participants consented for quotes to be used in the reporting of the research and for possible poster or conference presentations. They were also informed that they could withdraw from the research at any time. (See Appendix 8 for consent form.)

Before this research was conducted, ethical approval was obtained from the National Research Ethics Service Committee West Midlands - Coventry and Warwickshire (see Appendix 9).

The participants were informed that I was a PhD student and the research was part of my doctoral studies. I also made it clear that I was a dietitian and dietetics lecturer. I have conducted this research with honesty and integrity and have not misrepresented any of the findings.

4.9 Reflexivity and positionality

Reflexivity is a conscious and deliberate act undertaken by a researcher which helps to enhance rigour (Berger, 2015). It is the process of thoughtful self-critique to allow the researcher to develop self-awareness of how their own role might influence the research process (Finlay, 2002; Dowling, 2007). Thus, the researcher needs to be aware of their potential and actual effects on the research processes and findings (Berger, 2015), as researchers cannot avoid having an impact on the research process (Ahmed *et al.*, 2011). To do this, the researcher needs to reflect on their background as well as their assumptions, actions, emotions, and thoughts (Darawsheh, 2014).

A researcher's position within the research is often categorised as either an insider or an outsider, with an outsider being a 'stranger' and an insider having knowledge of the topic or communities (McDermid *et al.*, 2014:28). However, a binary distinction has been questioned with some authors

considering this to be more fluid and really a continuum where a researcher moves between these states at different stages of the research (Ben-Ari and Enosh, 2011; McDermid *et al.*, 2014; Milligan, 2014). It has also been suggested that the key issue in reflexivity is being able to be 'open, authentic, honest, deeply interested in the experience of one's research participants, and committed to accurately and adequately representing their experience' (Corbin Dwyer and Buckle, 2009:59). Therefore, how my views might have influenced the research process is important to consider because I was in-the-world of dietitians and I did not bracket my experiences. I needed to be aware of my pre-suppositions and to question and reflect upon them during the research process. Also, within interpretive phenomenology the researcher and the participant are co-investigators, so my assumptions and experiences may influence the research (van Manen, 1990). Reflexivity should occur throughout the research process, that is, during the planning of the research, the data collection, and data analysis.

4.9.1 Planning stage

During the planning of the research it is important to approach the research with openness, as there is a risk of starting the interpretation before any data has been collected (van Manen, 1990). My pre-understandings or pre-suppositions, assumptions, and thoughts about what the research might reveal needed to be considered. Therefore, during the planning stage of this research I reflected on my clinical

experience, my personal views about ANH, and my view of professionalism within dietetics.

My clinical experience contributed to my interest in the topic area for example, why we feed some patients and do not feed others. I remember as a newly qualified dietitian being uncomfortable when patients were left with intravenous fluids but received no nutrition. I am a senior and very experienced dietitian, so I also reflected upon differences in clinical practice: how would I respond if someone's clinical practice was safe, but just different to mine? Would I want to be treated by that person? I also reflected on my experience of supporting students on clinical placements. I visit students on placement and they describe a range of experiences. Some receive excellent support, while others do not. Some students have also talked about difficult situations related to ANH when the dietitians were not directly involved with the decision. Some students found that difficult as they had undertaken their placements expecting dietitians to be more involved in decisions. Although I had already experienced this, it helped to remind me that a dietitian may be knowledgeable and skilled but may not always be involved in a decision. I tried not to let these experiences influence the development of the research and topic guide. I was mindful that I needed to ensure that my topic guide, questions, and probes were not trying to catch people out; I was not testing their knowledge, but I was exploring their experiences. Also, although someone's practice might be different to mine it might not mean it was wrong. As I was likely to find a range of experiences, I needed to develop

a topic guide and questions which were open, would encourage reflection, were not leading, and would not suggest that any judgements were being made on my part.

I have strong personal views about ANH. I do feel troubled that some people seem to have a poor quality of life when they receive long-term ANH; they appear to be just kept alive by ANH, and I would not want that for myself. I feel troubled by these kinds of difficult cases on a number of fronts. Is this what a patient would want? Is this really what families want? Why is death and dying still a cultural taboo? I also wonder about the use of precious NHS resources. Often we do not seem to have the courage to talk about these issues. As a result of case law concerning not withdrawing ANH for a patient in a minimally conscious state (*W v M*, 2011), I have appointed a lasting power of attorney. He has been advised that I would not want to receive life-prolonging ANH if I am likely to continue with a long-term condition where I do not have capacity to make decisions. Therefore, during the development of the topic guide I needed to get the balance right between exploring an issue I am personally interested in and focusing on the participants' experiences. I am not the only one who has these strong views, but I am mindful that not everyone does. So while this is a topic which needed to be explored, it needed to be explored from their viewpoint, not mine.

I teach professionalism on a dietetics course and I have strong views about professional norms. I think I have what might be perceived as an

'old school' professionalism. I believe that appearance and conduct are part of professionalism. However, I do have problems with some professional norms that suggest it is wrong to get emotional even when situations are clearly emotional. I was mindful that there was a risk that I would direct questions towards experiences which were emotional. While I was interested in that experience, I was careful to develop the topic guide to explore it through their experiences rather than asking leading questions about emotions.

From my reflections outlined above, and from reading survey literature about dietitians and decision-making about ANH, in the planning stages I thought that *some* dietitians would not be able to reason their decisions, and that they would just be following instructions and not be actively involved in decision-making. Therefore, there was the risk that the interviews would not allow for deep exploration of their thinking because I did not think it would be found. Indeed, the topic guide used in the first interview, developed during the planning stages from a tool which was superficial, to one which did allow for deep exploration of experiences and the complexity of clinical situations, which allowed the participants to deeply reflect and explore their experiences. It was the process of thinking about the range of experiences that I might find, and discussions about how I might reveal more of the experience, which enabled the topic guide to be refined and developed, and for me to consider how I would conduct the interviews to facilitate deep reflection.

4.9.2 Recruitment stage

In interpretative phenomenology it is important to recruit people with an experience of the phenomenon of interest, therefore in this research I needed to recruit clinical dietitians with an experience of involvement in decisions about ANH. It was decided to recruit from the West Midlands for the pragmatic reasons of ease of travel to interview the participants.

However, this did mean that participants might be known to me, either as previous work colleagues or previous students. For some researchers this may result in them being an 'intimate insider' if they had a 'pre-existing personal relationship' with the participants (McDermid *et al.*, 2014:29).

However, I knew this would not be an issue for me, as I do not have personal relationships with dietitians. However, it was highly likely that some participants I recruited may be known to me, therefore I needed to consider reflexivity in the recruitment of participants.

Power dynamics can come in to play during the recruitment of participants. It has been suggested that at the recruitment stage the researcher holds the power (Karnieli-Miller *et al.*, 2009; Milligan, 2014); however, the researcher is at the mercy of the participants as without them there is no research. Due to this possible power imbalance the researcher needs to be mindful of coercion. Coercion may occur when participants feel pressured to take part in research. The risk of coercion is greater when the participants know the researcher, as they may feel it is difficult to decline to take part in the research, or feel they have no choice but to take part in the research (McDermid *et al.*, 2014). The risk of coercion was reduced in

my study as the first contact was via an email from a gatekeeper (the chairperson of the West Midlands branch of the British Dietetic Association). No pressure was placed on the potential participants to reply, and the primary message was only sent once, so it could easily have been ignored by the recipients. Using the gatekeeper to send the message empowered potential participants to only contact me if they wanted to find out more about the research.

Hiller and Vears (2016) suggest that to reduce the risk of coercion it should be easy for the potential participants to refuse to take part. In my research it was easy for potential participants to refuse as they had to actively opt in to taking part; they had to contact me to get an information sheet for further details of the study. Only at this point did I receive their contact details. However, I was still careful not to put undue pressure on the potential participants. Once I received an email expressing an interest in the study, I sent them the information sheet and a request to arrange a time to phone them to discuss the study in more detail. If within two weeks there was no reply, one follow up email was sent. If there was still no reply, I did not pursue them further. Two dietitians did not reply after the information sheet was sent. One participant withdrew before the first interview was conducted, suggesting she did not feel pressured to continue with the research. Also to reduce the risk of coercion, the information sheet clearly indicated that participation was voluntary and they could withdraw from the research.

4.9.3 Data collection stage

The method of data collection used in this research was one-to-one interviews, therefore my position and relationship with the participants was important to consider. Clancy (2013) suggests that the researcher needs to have an awareness of themselves by considering factors such as life experience, age, identity, role, ethnicity, and gender, and when exploring clinical practice, professional role or status is also likely to have an important influence. I had multiple identities in this research. I was primarily a researcher, but I am a dietitian and a university lecturer of dietetics. All these could have influenced my relationship with the participants, which in turn could have influenced the data collected.

Researchers can be considered insiders when they share characteristics, roles, or experiences with their participants (Corbin Dwyer and Buckle, 2009). I could be considered an insider, as I am a dietitian who undertakes clinical work, and I have experience of decision-making about ANH, so I shared a common lived experience, identity, and language with my participants. I understood the jargon used during the interviews and could use the 'right' language which Rhodes (1994) suggests might be advantageous, as I was able to explore the meaning of what the participant recounted when knowledge might be tacit. I tried to be mindful to reflect and explore the participants' meaning, rather than just make assumptions that I understood what they meant or accept my own preconceived ideas. Ajjawi and Higgs (2007) describe this as hermeneutic alertness. Being an insider may also have a positive effect on bonding

and rapport (Clancy, 2013; Hiller and Vears, 2016), which might have resulted in the participants having a greater degree of trust in me, which contributed to the collection of rich data. Berger (2015) suggests that participants might be more willing to share their experiences with an insider, as they may believe them to be sympathetic to their position or be understanding of their situation. Kane and O'Reilly-de Brun (2001) suggest that being an insider can also mean that nuances can be picked up and that the researcher will be more aware of what participants are not saying. This can lead to probing to explore these points further. It has also been argued that being an insider enables greater critical awareness of one's own experiences which can aid reflexivity (Gair, 2012).

However, there may be negatives associated with being an insider. The research might have been constrained by my personal experiences and viewpoints. There was a risk that I would make assumptions because I thought I knew what participants meant, or things might go unnoticed because they were commonplace to me (Breen, 2007; Clancy, 2013). I also had professional relationships with some participants; I had worked with some of them, and some were previous students I had taught. Therefore, there was a risk that they might have thought that they knew what I wanted to hear and so said certain things because they knew me. Where I knew participants, I said that I wanted to hear about them anew, so as not to make assumptions about what I already knew about them. For one participant I said:

'I know you and I know what your background is, but for the tape [laugh]. You said that those, umm, values came from your previous experience, so can you tell me a little bit about your previous experience?'

Although being a dietitian does suggest being an insider, I may have been viewed differently by some participants because of my role as a university lecturer. I may have been perceived by some as someone who was knowledgeable, had status, and who was checking up on them.

Alternatively, I may have been viewed as someone who is out of touch with clinical practice because I do not get my hands dirty or do any real clinical work.

It is often accepted that there can be power imbalances between the researcher and the participants of a study (Breen, 2007; Gair, 2012). Social systems will apply in a research setting, and the participants may perceive the researcher as being more knowledgeable or educated than themselves (Johnson-Bailey, 2008). Being an insider may have helped to reduce these power imbalances a little, as I made it clear that I was a clinical dietitian and that I was not assessing or testing them. Indeed, Hiller and Vears (2016) note that it is not uncommon for healthcare professionals who are being interviewed about their practice to ask for feedback, although I did not experience this. While I could have talked in detail about my clinical experience I decided not to as I did not want to influence their account; it was also important that I allowed the participants

to recount their experiences and not be influenced by mine (Brunero *et al.*, 2015). I tried to distance myself a little, to try to keep a professional stance as a researcher, rather than chatting to a dietetic friend, therefore I did not share any of my experiences or views of ANH so as not to influence the participants as recommended by Berger (2015). I kept the focus on *their* experience. I was mindful of how I acted, as I did not want it to appear as if I was judging them. I needed to be aware of my thoughts and feelings and at times not show them. I considered my tone of voice and body language, particularly when dietitians talked about things I would have done differently. I was especially mindful of this with some of the more experienced dietitians who practised in a very different way to me. There were also times when I worked hard not to show that I was irritated by the responses given. I wanted answers to my questions and some participants tended to sidestep questions. These were often related to my questions about the emotional aspects of the experience. This may have been due to their perceived professional norms of not showing emotions or getting involved with patients. While I tried to overcome this by gently probing for more detail, I respected them and did not force them into giving answers when they did not want to. Perhaps this suggested some did not feel a major power imbalance or did not feel bullied into talking about things they would rather not. Indeed, some participants corrected me when I incorrectly paraphrased them.

Interviews are a two-way process; the researcher will influence the participants, but the participants can also influence the researcher

(Underwood *et al.*, 2010). Clancy (2013) suggests that the researchers' thoughts and feelings will influence participants; for example, the researcher may influence how the participants act, what they say, and what they share about their experiences. Therefore, I reflected on the first interviews before undertaking the second. I reflected on the fact that I was looking forward to talking to some participants more than others. I knew that some interviews would be harder work than others and I was looking forward to re-interviewing those I considered to be very experienced and knowledgeable, who I respected greatly as clinical dietitians. When reflecting on the first interview, I considered what worked well last time, what was different about this interview compared to others, and how might I need to change my approach. Was it me influencing them or them influencing me? The field notes I kept after each interview helped with this process. (See Appendix 10 for some excerpts from my reflexivity diary about some of these experiences.)

Factors such as ethnicity and gender can also influence the data collection process (Williams and Heikes, 1993; Rhodes, 1994; Padfield and Procter, 1996). I am white and female, as were all the participants in this research, so any effects are likely to be small. However, social distance effect is also useful to consider, that is, how similar were the participants to me, as Hoong Sin (2007) notes that this can influence power relationships, and age may be a factor (Etherington, 2004). The ages of the participants varied from early 20s to early 50s. At the time the data was collected I was 42 years old. Therefore, I was similar to some participants, but the majority

were younger than me. So while I did put measures in place to mitigate this as outlined above, the age differences may have influenced the perception of power for some of the younger participants.

I tried to ensure that I treated all participants with care, compassion, and respect, and some participants discussed some very deeply personal experiences, suggesting that they felt at ease and trusted me. Overall, I believe that I had the trust of my participants, and as dietetics is a small profession it is important to respect this and protect my participants' anonymity. This is especially important where participants are known to the researcher, due to the risk of reprisal if their identity became known (McDermid *et al.*, 2014). I did this by removing some key aspects of unique roles that some dietitians undertook in the West Midlands, as this would have identified the dietitian. I ensured that I did not change the meaning of the data in any way, and to empower my participants they were asked to check that they were happy with the changes I made in order to protect them.

4.9.4 Data analysis stage

Reflexivity needs to continue during the data analysis stage. Therefore, after the data was collected, I reflected on the interviews and my participants' experiences. I think initially I fell into the trap that Clancy (2013) calls role confusion, where data is analysed from the perspective of the clinician rather than a researcher, which can lead to premature

conclusions being drawn. My supervisors soon guided me to a more reflexive data analysis.

It was only as I immersed myself in the data, and considered the participants' experiences deeply, that I really appreciated the range and complexity of them. Although I was immersed in the data, Brunero *et al.* (2015) note the importance of being able to detach oneself in order to be able to think about the data in a theoretical way. Initially, I thought that some participants' practice was not what I would wish to receive if I was a patient. However, the participants' accounts revealed so much more than right or expert practice. In fact, some of the richest data came from those who were not experts. Therefore, my view of these dietitians changed as they had deep and complex experiences.

I did not bracket my views as I believe that I could not separate out my knowledge of being a dietitian. As a researcher I did have insider status, although my supervisors were outsiders, which helped to balance my insider status (Brunero *et al.*, 2015). My supervisors challenged my interpretation of the data. That in itself was a challenge as there is a power relationship between student and supervisor (Valandra, 2012). I was grateful for their guidance with the massive task of data analysis, but I was mindful that it was my data; I conducted the interviews and so it needed to be my interpretation of the data. They were not present at the interviews, and given the nature of interpretive phenomenology, their interpretation might have been different to mine.

The product of the data analysis is the findings, in this case, the story which illuminates the experience of dietitians' involvement in decisions about ANH. The experiences were illustrated by quotes from participants, which should increase transparency. However, reflexivity is also needed at this stage, as it is the researcher who decides whose voice to reveal and what story to tell (Wilkinson and Kitzinger, 2013). Indeed, participants may feel uneasy about how they are presented in the results of research (McDermid *et al.*, 2014). As I knew some participants, and dietetics is a small profession, I was mindful to ensure that I was accurate and that my participants were presented in a professional and respectful manner (Berger, 2015). As a dietitian and insider there is the risk that I would want to present my profession in the best light possible. However, I believe I have presented an open and honest account of dietitians' experiences.

4.10 Conclusion

In this chapter I have outlined the research question and objectives for the research. This research has answered the question, 'What is the experience of dietitians' involvement in decisions relating to ANH?' To answer this question, in-depth reflective accounts of experience were obtained to explore the participants' life-world and understand and interpret their experiences. This research has given voice to dietitians' experiences and brought to light what was normally hidden.

I have justified the approach of interpretive phenomenology and distinguished between phenomenology as a philosophy and a methodology. I have demonstrated that the methods of data collection and data analysis are congruent with interpretive phenomenology and have shown that I adopted processes to enhance rigour, such as method triangulation, member checking, peer review, and reflexivity. These will be discussed in more detail in the discussion chapter.

The focus of the next chapters of the thesis will be an exploration of the findings revealed in the research. In particular, that dietitians adopt many different roles, that they want to be involved in decisions, that decision-making is emotive, and how dietitians responded to these emotions. The discussion chapter will discuss the findings, and finally the last chapter will summarise the research, draw conclusions, and consider the quality of the research. Originality and contribution to knowledge will be outlined and implications for practice, training, and professional organisations will be suggested.

Chapter 5: So much more than just deciding on a feed

5.1 Introduction

Most healthcare professionals would agree that dietitians have a key role in the provision of artificial nutrition and hydration (ANH). There is an expectation that dietitians should form part of the team involved in hospital and community feeding services, as they have the skills to identify, assess, plan, and monitor patients (National Institute for Health and Clinical Excellence, 2006; The British Dietetic Association, 2012b). In this chapter I will explore the varied roles evident in the dietitians' accounts of their everyday involvement in decision-making related to the provision of ANH. Their accounts suggest that these roles were varied and can be complex. The roles encompassed more than just the technical duties, such as the assessment of patients, calculation of requirements, the making of a therapeutic plan, the implementation of the plan, monitoring of patients, and professional activities such as team working, which have been described by others (Jones *et al.*, 1986; Skipper and Rotman, 1990; Olree and Skipper, 1995; Boyhtari and Cardinal, 1997; Olree and Skipper, 1997; Stanley and Borthwick, 2013). Their accounts illuminate a number of roles not previously identified in studies with dietitians but which appear to be part of their everyday lived experience. It is these accounts which will be the focus of the chapter.

In the dietitians' accounts of their experiences of decision-making related to ANH, it became evident that they adopted roles as experts, educators,

advocates, and technicians. Some roles were associated with normal dietetic practice, whereas others were related to more advanced clinical specialist roles. The dietitians described how they were involved in decisions to a greater or lesser degree and that their role with regard to these decisions varied. Both the extent of the dietitians' involvement and the roles they described depended on the situation, the type of decision, and the involvement of other healthcare professionals. The roles were not necessarily distinct but appeared to overlap and be linked, so to explore these roles and define them clearly I have separated them. Some of the roles were clear and well defined, but others were more nuanced and less well articulated by some dietitians.

5.2 Dietitian as an expert

All the dietitians appeared to feel that they had an expert role in decision-making because they were the specialists in nutrition. Some accounts also highlighted that they were regarded as expert by others. Specific areas of specialist expertise appeared to vary depending on the place of work and experience of the dietitian. All the dietitians talked of being experts in assessing patients and providing nutrition support. As this role is considered core to the role of dietitians, and described elsewhere (Jones *et al.*, 1986; Skipper and Rotman, 1990; Olree and Skipper, 1995; Boyhtari and Cardinal, 1997; Olree and Skipper, 1997; Stanley and Borthwick, 2013), I will focus on the other expert roles that some or all the dietitians recounted and have not been previously described.

In all the dietitians accounts, their role in giving advice to medical teams on the timely and appropriate use of ANH by assessing patients and advising the medical team on options for nutrition support was evident. Some dietitians, however, appeared to feel that this advice was not always taken. About half the participants (mainly senior acute care dietitians) discussed how their view was actively sought by the medical team, reinforcing the feeling of being an expert, which was a positive experience for them. A senior trauma dietitian discussed how the team she worked with appeared to recognise her expertise:

'I mean trauma surgeons by background are not particularly nutrition orientated and I had some of them who hold their hands up and go, "No idea [dietitian's name] you tell me". Which is quite nice in a way because you can actually say, "Right this is what we need to do." We've got a couple of the sort of consultants that have said "You tell me what you want and we'll do it", which is quite nice.'

P16, senior acute care dietitian

Before ANH can start, decisions need to be made about how to provide the nutrition safely. All the dietitians' accounts made reference to how their role included the assessment of the risk of refeeding syndrome, a potentially life-threatening consequence of starting to feed someone who is malnourished too quickly. The dietitians appeared to believe that they had a consultant role in this area; they assessed risk and communicated to the medical team the best management options to reduce risk. The dietitians also discussed how they ensured that the feed was provided in

such a way as to reduce the risk. However, tensions were expressed in this area. Although the dietitians seemed to believe they had a lead expert role in reducing the risk of a patient developing refeeding syndrome, some described situations where the medical team did not always follow their advice. These dietitians associated this to either a lack of awareness of the risk of refeeding syndrome or a lack of concern about the risks associated with refeeding syndrome by the medical team. Two dietitians' accounts illustrated this:

'And it's the same with the refeeding syndrome. Some people [doctors] don't know about refeeding syndrome so you have to explain that to them. And every new doctor that comes on you end up re-teaching them.'

P1, junior acute care dietitian

'I remember speaking to the consultant saying I think he's at risk of refeeding. Can we check some bloods, and he was difficult to bleed. And the consultant said, "Oh refeeding syndrome's very overrated, just feed your patient up." And that's the sort of attitude of a lot.'

P5, junior acute care dietitian

A lack of awareness and the perception that refeeding syndrome is not important has been noted before (Skipper, 2012), and appeared to lead to some dietitians' requests for blood tests or prescriptions for supplements to correct any biochemical anomalies being ignored. These accounts illustrate how these dietitians were conscious that sometimes their

expertise was not recognised. This will be explored further in the next findings chapter 'Wanting to be heard'.

Just over a quarter of the participants considered that they played an expert role in the assessment of patients' capacity to make decisions related to ANH, particularly in relation to the insertion of a percutaneous endoscopic gastrostomy (PEG) for long-term feeding. These tended to be more senior dietitians, especially those who worked in community settings. Acute care dietitians did not report this role so often, probably because within a hospital setting this is traditionally a medical role. However, in a community setting the dietitians were of the view that often, the medical team or GP were not always closely involved with the patient, so the community dietitians took on the role of assessor of capacity as part of their overall assessment of the patients' suitability for ANH. One community dietitian said:

'I spoke to the staff afterwards. They said, "She does tend to agree to things when mum's there. But when you go back and ask her she'll say no." So that then I thought, "How does that reflect on her capacity?" ...[and] as far as decision by decision, I do think that if you've got the most information about that decision then it should be you [that assesses capacity]. So I kind of think it should be me that makes that decision about this one.'

P4, senior community dietitian

This dietitian appeared to use her expertise to consider if a patient had capacity for decision-making. While UK dietitians have been encouraged to be involved in this role in their implementation of the Mental Capacity Act (Lyons *et al.*, 2007) reports of UK dietitians actually doing this are lacking. In the survey of Canadian dietitians by Szeto *et al.* (2014) 40% stated that they always or usually evaluated a patient's competence.

A few dietitians used their expertise to make decisions about timely referrals to endoscopy services for PEG insertion because in some progressive conditions there is a small window of opportunity for PEG insertion. Dietitians appeared to believe that this window was when the swallow had deteriorated enough to make a PEG indicated, but not so much that the patient had become malnourished. Respiratory function also needed to be considered within this timeframe, as if this had declined a PEG cannot be inserted.

All dietitians described how they used their expert knowledge to offer patients different options to enable them to make informed decisions regarding their treatment choices, such as the delivery of the feed. One dietitian talked of using evidence in order to enable patients to make informed choices about their care:

'One oncologist believes that pump training and pump feeding patients seriously puts them back...as far as my knowledge and understanding is, there's no evidence to say otherwise. And I think unless he comes up with a really great article or great journal article

or studies that have been done to show me otherwise, I think it's just as acceptable a method [pump feeding] as bolus feeding. And I think it's the patients' decision not his. Whether they want to bolus feed or pump feed or do a little bit of both...If the patient doesn't have all the information how can they make an informed choice?

P14, junior acute care dietitian

All the dietitians considered themselves as being the best-placed people to give this information because they used their expert communication skills and knowledge to take the complex language that other professions might use (for example, doctors) and translate it into something that patients could understand. Good communication skills appeared to be essential to facilitate this expertise, with about half the dietitians talking about their advanced communication skills training which helped them in this role. Developing these skills has been identified as key in the dietetics literature (Cant and Aroni, 2008; Whitehead *et al.*, 2009; Power and Lennie, 2012). Some of the senior dietitians described how they used their expert knowledge and communication skills to talk to patients and carers about the risks and benefits of receiving ANH. They appeared to try to give a realistic view of what receiving ANH in a community setting might be like. Some also explained that ANH was a treatment in itself, and as such could be withdrawn if it was no longer of benefit. The motivation for explaining to patients that ANH could be withdrawn seemed to be to reduce the burden for patients. The following quotes illustrate this:

'We talk about NG feeding and we expect everybody to know what it is, but actually you know, so sitting down and explaining to them what it is and, umm, you know, that actually it is part of the treatment, and part of the treatment we can take away, if it's not of any benefit.'

P13, senior acute care dietitian

'I would just try and give them the facts that well, this will have to happen. They will have to have people coming in three or four times a day. You will have to care for it yourself, you'll have to, you know. Ermm, and hopefully that helps them to make a decision, a better decision rather than just thinking it's all going to be rosy when it's not.'

P4, senior community dietitian

The dietitians' accounts suggest that they were able provide this information to their patients because they had expert knowledge and many had the experience of seeing patients in their own homes and heard the problems they encountered. The dietitians understood many of the practical issues that patients may face when receiving ANH.

All the community dietitians who worked with patients that had progressive conditions described a more specialist expert role of PEG counselling. These patients may be faced with making a decision in advance about whether to have ANH, when and if their swallow became unsafe. It has been suggested that they should be advised on their treatment options

and helped to come to a decision about whether a feeding tube is wanted, at what stage it should be inserted, and what the practical implications of having that tube might be (Miller *et al.*, 2009). The dietitians who took on this role used their expert knowledge of feeding, and practical experience of what it was really like for many patients to receive ANH via a PEG, to help patients with decision-making. This expert knowledge enabled a real life 'warts and all' picture to be painted to ensure that patients have an as real as possible indication of what long-term feeding might be like for them, to support patients in their decision-making.

'And usually within the first couple of consultations I'll mention PEG...If there's somebody you think won't be able to cope with the PEG and it will change their life completely because of health visitors coming in to deal with it and that sort of thing then I will voice that...I would just try and give them the facts that well, this will have to happen.'

P4, senior community dietitian

'I do like to get involved with the PEGs. If a PEG's being placed then usually I am involved at that stage because they've been NG feeding. We've got an information booklet we've put together now which I give to patients or carers, whoever is appropriate. Erm, if I know PEG's been thought about. And it just gives them a bit more information to help them decide whether it's the right thing for them. And doctors seem to appreciate that...I like to get in there. If the family visit regularly, and it's you know, I like to get into there with

them and explain what it's going to involve down the line. Just to get them thinking about it long term.'

P11, senior acute care dietitian

Many of the dietitians also described how their expert role involved them talking to patients, family, or carers about PEGs long term, especially when a patient had a naso-gastric (NG) tube and long-term feeding was indicated. Most dietitians felt that they took on this lead role in providing information in order to empower the patient and family in their decision-making. A couple of community dietitians believed that they were experts because of their wide experience, but for P6, also because she knew her patients:

'I think one of the fundamental things that will help you with that type of patient [motor neurone disease] is that you know them. You know their set up...You could have the most experienced dietitian in the world, but they haven't seen their home, you know, they haven't, erm. They also struggle a bit to link in...I've enjoyed doing that role and I think it is a key role...I think a dietitian's a good person to do it because they can also cover the whole thing about equipment, about the feeding, about the flexibility of that. It means that you're [the patient] not seeing five people when you could see one. And they don't get misinformation.'

P6, senior community dietitian

'And I have to remember that everyone sitting around the table, I'm the one who knows the most about PEG tubes. And I've got the

most experience as seeing what happens after they've had a PEG tube and I have to have the confidence to say that...I realise that they don't know as much about it as I do, you know. GPs see a few, I've got 135 patients. And that never really varies, so that's quite a depth of experience there.'

P4, senior community dietitian

Undertaking these expert roles had positive outcomes for some. One dietitian expressed some of these positive outcomes when she said:

'But I find the consultants, one of the consultants anyway is, erm, quite appreciative. He's quite approachable, he's quite appreciative of having a dietitian in the team. Much more, thinks about PEG feeding now as an option. And, erm, will ask my opinion on ward rounds.'

P11, senior acute care dietitian

This dietitian seemed to feel that her advice to the team had raised the profile of options for providing ANH and she was more involved in the team as a result, which was a positive outcome for her.

American dietitians have reported that being respected as experts and giving advice to the team was a positive aspect of their work (Devine *et al.*, 2004; Szeto *et al.*, 2014), although this has not been noted in UK dietitians before. Nurses who are viewed as experts are more likely to be involved in decision-making (Bryon *et al.*, 2010).

5.3 Dietitian as educator

During the interviews a clear role that was evident in all the dietitians' accounts was that of educating other healthcare professionals about ANH. All the participants believed that many other healthcare professionals had poor knowledge of nutrition, ANH, and related aspects. All the acute care dietitians discussed inappropriate referrals being made for ANH or for requests to increase protein in a prescribed feed due to a drop in a patient's serum albumin. When they had the opportunity, the dietitians tried to educate the medical team, as the following two quotes illustrate:

'One of the registrars last year started to talk to me about this patient's albumin [which] was low, "What are we going to do about it?" And I started to explain to him about that, actually that wasn't really the issue. It was low because he'd been in 15 hours of surgery. I started to explain this to him and he was just enlightened by it. He seemed quite genuinely appreciative that I'd actually taught him something new.'

P9, senior acute care dietitian

'And he sat down and asked me how I calculate requirements and how I start a feed. He just didn't know anything. He really didn't. He was like, "What time do you start a feed?" Well I was like, "Well you can start it anytime." He was, "What you don't have a set time that you start the feed?" It was just so strange that he just didn't know.'

P7, junior acute care dietitian

This data illustrates how dietitians acting as educators were fulfilling a role that was expected of them. The British Dietetic Association (The British Dietetic Association, 2008b; The British Dietetic Association, 2010) states that dietitians should be able to act as a resource for nutrition.

5.4 The dietitian as an advocate

In some situations advocacy can be regarded as an important part of patient-centred decision-making and includes the areas of safeguarding patients' autonomy, acting on behalf of patients, and championing social justice in the provision of healthcare (Bu and Jezewski, 2007). Patient advocacy means speaking up for the patient when they feel powerless or when they may be 'voiceless'. Effective advocacy empowers patients and can enable them to be more involved in decision-making (Woodrow, 1997; Bateman, 2000). Therefore, providing information to patients is key to patient advocacy (Woodrow, 1997; Bateman, 2000). Advocacy requires the professional skills of communication and negotiation which may be needed to avoid conflict (O'Connor, 2005; Bu and Jezewski, 2007).

Power and influence have also been recognised in the nursing literature as being needed for advocacy, and empowerment of staff may be needed to achieve this (Hewitt, 2002). O'Connor and Kelly (2005) suggest that advocacy can be divided into two broad categories: clinical advocacy and organisation advocacy. Clinical advocacy includes respecting patient autonomy and acting on behalf of patients, and organisational advocacy is related to policy and practices which affect patient care. In discussing their

lived experience of decision-making in ANH, many of the dietitians described an advocacy role, either in clinical patient advocacy, or in organisational advocacy for nutrition and dietetic services.

5.4.1 Clinical advocacy

In clinical advocacy it has been suggested that healthcare professionals need to speak on behalf of the patient when they are not able to effectively do so themselves. Within nursing it has been suggested that clinical advocacy also means giving information to patients to help with informed decision-making (Bateman, 2000). Therefore, helping patients understand information that is given to them and helping them to consider what might be best for them forms part of clinical advocacy.

The dietitians' accounts revealed both explicit and implicit descriptions of clinical advocacy. The following quotes illustrate how some dietitians discussed how they battled and negotiated for their patients. This included the need to haggle on behalf of the patient to get agreement from the team:

'The haematologists are great, but you know it's very hard to get them to actually feed anybody...when it comes to, like the tubes...you have to sort of say, I think we really need a tube now please! [hands in praying sign].'

P10, senior acute care dietitian

'But probably with those types of patients that are not mobile, especially the spinal patients, physically eating when lying as flat as

they are can be very very difficult. And often we have a bit more of a fight with them to try and get them to be fed.'

P16, senior acute care dietitian

'I wouldn't say that recently we've had a kind of major battle to get tubes in. There's always the odd one or two patients that it does feel that it's a kind of uphill struggle just to get in a tube.'

P16, senior acute care dietitian

'...the consultants are used to dietetic input so they're used to us...fighting for it if we need to...When [the doctors] they're thinking of the medical condition rather than the sort of holistic, everything else that is going on, then obviously it's something worth really fighting for...but yes, sometimes it can be a fight.'

P5, junior acute care dietitian

One dietitian described how exhausting these battles were:

'We have this saying in our office: "It's like swimming through treacle" and that's how it feels some days, you know. And your arms are tired and you can't be bothered any more. And some days you do give into it and just think, "Oh" and, "I can't deal with that today, I really can't put up that fight today". And then you just do it the next day instead. And you just hope that the next day you feel that you want to fight. And it is like fighting quite a lot of the time. And you, it depends what you've got going on yourself personally as well. Because if anything's weighing on your mind personally

you just haven't got the fight in you to do it. Then sometimes you get angry and think, "God I shouldn't have to fight so hard to get things done". Sometimes you want to just lie down and give up and not fight any more. But you do, you bounce back, you know, in a couple of days later you think, "Right, let's tackle that issue".'

P4, senior community dietitian

Other dietitians gave accounts of time spent finding out what was important to their patients from a treatment goal point of view. All the participants talked about their role of collecting information from patients, or family members and carers. This covered a range of topics, such as treatment preferences or beliefs about extending life. This enabled dietitians to act as advocates by either speaking up for the patient or by trying to ensure that their values were respected during decision-making. Patients with chronic medical conditions are often well known by their dietitian, so that puts the dietitian in an ideal position to explore the patients' beliefs and to properly discuss their options. Participants' accounts included developing relationships with patients to aid advocacy and trying to put themselves in the patients' position in order to imagine what it might be like to prompt clinical advocacy.

'And as soon as we have a referral, they are referred to me now, which is something that I changed. They used to wait until they actually got an issue with eating or swallowing but I said I'd rather they just referred and I get to know them, build up that relationship...So I'm guided by what they want really.'

P4, senior community dietitian

'I sit there trying to imagine myself in their position...they'll [the nurses] be telling people to drink two litres of rehydration solution a day and I'll be thinking, "for crying out loud, I can't even drink 200ml of it"...And they'll [the nurses] be saying you've got to drink five, you know. The consultant always says, if we stop the TPN [Total Parenteral Nutrition] you've got to drink four of these supplement drinks, and I know I wouldn't be able to drink them. So it is that, I don't know, [pause], patient advocate and all that. I know, all these terms, I would like yeah, I do find myself trying to put myself in their position.'

P13, senior acute care dietitian

As part of their clinical advocacy role, some participants felt it was their responsibility to check that patients had consented; whether that was to receive ANH, have a tube inserted, or to use a restraint to stop a tube being removed. They appeared to feel it was their duty to check the patient had agreed to it, so respecting the patient's autonomy. A couple of dietitians stated:

'I'd say that we'd have the conversation [do you want ANH] with the patient if we can, we have the conversation with the patient, actually [pause], sometimes even before you speak to the referrer about it. Because you go to the patient to assess them, to see what they want.'

P13, senior acute care dietitian

'Before she started using the PEG for nutrition I did want to kind of confirm with her that it was what she wanted. So I did actually ask a more direct question...“Are you okay with this?”'

P8, senior community dietitian

The importance that some dietitians placed on checking that patients had consented seemed to be based on their experience of situations where they had concerns that patients had not consented. Dietitians speaking out about this contributes to the next chapter on 'Wanting to be heard'.

5.4.2 Clinical advocacy - Best interests decisions

Within their clinical advocacy role, just over a third of dietitians were involved in best interests decisions. These are decisions made when patients lack the capacity to make a decision for themselves. As stated in the Mental Capacity Act, when making best interests decisions, a patient's past and present wishes and their values and beliefs should be taken into account (Department of Constitutional Affairs, 2005). Therefore, if a patient's wishes, values, and beliefs are known by a dietitian, they should act as a patient advocate and speak up for the patient to ensure that their wishes are shared with the rest of the team to inform a decision.

All the dietitians involved in best interests decisions felt that the decision should be made as a team, and should include the patient's family as well as the wider healthcare team. Many dietitians felt their role was to collect information about the patient from the family, nursing staff, and other

health professionals in order to act on behalf of the patient within the decision-making process. This information was then shared with the rest of the team.

'But if somebody's going to talk to you about it and they're going to express a strong desire then I feel you need to report it back to the rest of the team, because you can't just ignore what they've said.'

P12, senior acute care dietitian

Some dietitians discussed how the involvement of the patient's family could support best interests decision-making, or at other times could make it more difficult. Some welcomed families for being involved in decision-making, especially if they clearly showed they had thought about what their family member would have wanted, as it enabled clinical advocacy. This dietitian believed that a decision to provide ANH was facilitated by the family thinking about their mother rather than making general statements:

'It was [clear] that they were thinking about her...because sometimes...they could be talking about anybody or it's about what they've read in the papers about people being starved...But they [the family] were talking about how she liked the nursing home and she was quite thin...'

P13, senior acute care dietitian

However, others expressed concern that family members may not have been expressing the wishes of their family member but their own views and wishes:

'...it's difficult because you're not able to ask him [the patient] anything and determine what he wants. And you have to sort of rely on the family's opinions. Which might or might not agree with the patient's.'

P11, senior acute care dietitian

Many dietitians discussed the holistic nature of best interests decisions. They used their knowledge of the patient's values and their advocacy skills to consider the balance of risk and benefits of a decision. This was discussed in holistic terms, not necessarily just as an extension of life; they felt that there needed to be quality to life, not just life per se. Two dietitians expressed the weighing up of harms and benefits in the following way:

'Bridle/PEG /dehydration/renal failure, [hands weighing it up]. It's the best of a bad bunch really and I think to me that's the better option than of either of the other two...[and] how dignified is having mittens on versus repeatedly passing an NG [nasogastric] tube?'

P9, senior acute care dietitian

'... is it going to do the patient more harm than good? I think that's the sort of main issue.'

P14, junior acute care dietitian

This balancing of benefit and risk suggests an ethical sensitivity in the accounts of these dietitians. Many seemed to accept that feeding was not always possible and they had to be realistic in their treatment plan. In

doing so, they appeared to be adopting the approach encouraged by the British Dietetic Association in their 'Model and Process for Nutrition and Dietetic Practice' that realistic goals for treatment are set (The British Dietetic Association, 2012a).

All dietitians felt that they should have some involvement in best interest decisions as part of a team.

'So you're often presented with a patient that...can't make those decisions for themselves...And it's doing what is in, what you feel, what the consultant feels, what the team feels are in that patient's best interests...you're making that assessment, making that judgement call as to the options for nutrition...And if they're not able to make that informed consent then the whole team, it's often a team approach coming together to say right this is what we're going to do.'

P16, senior acute care dietitian

'I think in the community we are better at reaching decisions by best interests process...I'll just give you the example of the patient that's coming up. She's got MS...And she's in complete denial about the fact that she can't swallow. She's lost a lot of weight quite quickly...So I talked to the nursing staff and we've agreed that we need to get a best interests meeting set up. Which will involve the GP, speech and language therapist, myself, nursing staff at the home, and her relatives - she's got a sister and a mother that are quite close.'

P4, senior community dietitian

The difficulties associated with best interest decisions were clear in the accounts from some dietitians. These were often around other people's reactions to the process of decision-making. The emotions are evident in these accounts and will be explored in the findings chapter 'The emotional roller coaster'.

'You just kind of make it clear it's not our decision [against ANH], we're going to have to make sure there's a best interest meeting. So just make it clear to them [the family] just what the process is and sometimes that helps. Sometimes it doesn't...I don't like seeing people upset about it I suppose. And I don't want people to think that we're just saying no because we've got the power to say no, because that's not the case.'

P3, senior community dietitian

'...usually they've [best interest meetings] gone quite well...But I've had one where relatives were firmly against having a feeding tube placed and the rest of the professionals felt that it was a good thing...That was hard, very hard. I actually came down on the side of the relatives...but everybody else felt that they should have had the feeding tube. It was horrible, really horrible. Because I think legally they can't make the decision for somebody but they know that person the best, you know. And everyone questions their motives...especially when you're trying to refuse a procedure.'

People do question, well they just want to bump them off and get the house and you know things like that. And I think that's awful...yeah, it's not very nice, it's quite upsetting really.'

P4, senior community dietitian

Some expressed concern when they were not involved because they felt they had the expertise needed for the discussions to inform these decisions. Some were concerned that hospital doctors did not have adequate knowledge of the long-term aspects of ANH following discharge from hospital on which to base a decision. One dietitian expressed this as:

'The consultants ask us about PEG feeding long term, so I don't think they know a lot about it. Which worries me because when they're talking to families they're not actually giving all the information.'

P2, junior acute care dietitian

This view appears to support the expert role of dietitians, as her view was being sought; however, she is troubled by a possible lack of good quality information being provided to the family.

5.4.3 Clinical advocacy - Advance directives

Clinical advocacy skills are needed when helping patients to draw up advance directives. A few of the senior community dietitians discussed how they helped patients drawing up advance directives and the importance of ensuring that the patient's views and wishes were captured.

One dietitian clearly described how she believed that an advance directive empowered her patient, but she acknowledged that with this clinical advocate role there was a huge responsibility:

'It's very difficult to do, write out an advance directive because you have to cover everything...But you can see that it gives them control back again of their life. And they're able to make their own decision about what they want...But I, the first time I did it, I had to call on the palliative care consultant, I didn't want to do it on my own. It's a huge responsibility. I mean what if you get the wording wrong... You just think what if, what if I write down that they don't want to be resuscitated and that's the wrong thing. What if they should be resuscitated? Who am I to, but it's not my, you know, you feel like you're making the decision but you're not. It is their decision, and with some people they've got such strong opinions that you know you haven't influenced them, you know it's entirely their decision. But you think, what if I have influenced them to do this?'

P4, senior community dietitian

This dietitian appeared to be very aware of the responsibility involved in taking on this role and was mindful of the possibility of influencing patients. While this dietitian appeared not to want to influence patients, paternalistic approaches to decisions where the health professional makes the decision they believe is most appropriate has been reported in patients with progressive swallowing problems, but mainly in acute care settings (Vesey *et al.*, 2008).

5.4.4 Organisational advocacy for nutrition and dietetic services.

Another aspect of advocacy is organisational advocacy, which is concerned with how policy and practice may affect patients. All dietitians' accounts acknowledged that there were problems with identification of malnutrition, referral to dietetic services, and initiation of ANH in some patients, and related this to issues with policies such as protected meal times and nutritional screening. Some dietitians suggested an awareness of the need for organisational advocacy, that is, to change or implement policy to improve patient care. While this is a complex issue, some appeared to feel that dietitians needed to play their part more by promoting the profession of dietetics more, to act as organisational advocates for the service to improve patient care. The two following quotes illustrate this issue:

'But again I think they [the doctors] didn't really realise what we did. Which I think is a dietetic problem. We really need to promote ourselves... We need to tell them! I think as a profession or individually just chipping away at it, and influencing.'

P2, junior acute care dietitian

'But I think we need to be a lot more vocal about that as well. I think we need to be more sort of in the faces of the stroke team. It's written that we should be a part of it, and I think we just need to push to make sure that we are.'

P5, junior acute care dietitian

These dietitians appeared to believe that as professionals, dietitians needed to be more proactive in promoting their role, which may improve their status and may lead to better nutrition services for patients. Some dietitians were more effective at this than others, which will be more fully explored in the next chapter on 'Wanting to be heard'. This seems to be an international issue, as the Dietitians Association of Australia guidelines on malnutrition include dietitians advocating for food services and malnutrition as one of the factors which can improve patient care (Walton, 2009).

5.5 The dietitian as technician

All the acute care dietitians described implementing decisions where they had not been involved in the actual decision-making process, so revealing a technician role, although the dietitians did not directly use this term. This is illustrated by the following quotes:

'...we have such little input in the decision, [it's] normally delivered in a, "We want this", or the tubes down and, "We want a regimen".'

P2, junior acute care dietitian

'...the surgeon will say [pause], "They'll need a PEG" and they'll look at me.'

P9, senior acute care dietitian

'Again I think he [the doctor] just expected us to come down and do the feed and then go home. Dietitians, they prescribe feeds, physios come down and move limbs type thing.'

P14, junior acute care dietitian.

These dietitians appear to suggest that they followed the orders of others, without having an input into the decision itself. All the acute care dietitians described this phenomenon, which many appeared to believe was due to the timing of the referral. If the referral to the dietitian was made after the decision to feed had been made, they felt that they could not influence the actual decision to feed.

In some situations dietitians were accepting of this role. However, in other situations undertaking this technician role appeared to lead to problems with some patients and frustrations for the dietitians. One senior dietitian suggested that some patients in her care might not have received ANH if they had been seen by a dietitian before a doctor:

'We've had a palliative care patient admitted for sort of getting her pain under control was only ever going to be TLC [Tender Loving Care]. Over a weekend ended up with an NG tube in and feed running...they [the doctors] hadn't thought about what were the implications of what they were doing.'

P16, senior acute care dietitian

For this dietitian the implications of feeding a patient when it was not indicated were of concern for her. The emotional experiences in the dietitians' accounts will be more fully explored in the findings chapter 'The emotional roller coaster'.

The fact that dietitians did receive the referrals, rather than another

member of the multi-disciplinary team, does suggest that there was a recognition that they had the right competency and skills needed. They are seen as the right person for the job. One dietitian was of the view that even if it was not her preferred treatment plan, at least the patient was being fed in a safe way by a skilled dietitian rather than the possibility of more risky feeding by another member of the team:

'Yeah, I think part of me knows that if I don't do the feed, the doctors will just turn around and put it up themselves, and basically just say "Well, we respect your comments but as a team we think this should be done." And if they're going to do a feed I'd rather it been done properly.'

P14, junior acute care dietitian

The lived experience of dietitians performing this technician role, the implementation of other people's decisions, has not been reported in the UK or international literature before. The reasons why dietitians are only being used as technicians and not being more directly involved in the decision-making process will be explored in Chapter 9.

5.6 Conclusion

In this chapter I have discussed the varied roles and skills that dietitians described as part of their everyday lived experience of decision-making related to providing ANH. While the roles were varied, they were all considered important for decision-making and patient care. For the purposes of this discussion the roles have been compartmentalised; in

reality, one role could feed into another and there were clearly overlaps in many roles. The roles of advocate and technician have not been fully described within dietetic practice before.

It is important to identify these roles in order to ensure that dietitians are adequately trained to take on these roles. It is also important to note the tensions between the roles of expert, educator, advocate, and technician, and for others to be aware of these roles to ensure effective team working. Tensions associated with the varying roles could create difficulties for the dietitians. For example, a dietitian may be advocating for a decision they may not agree is the best one. These varied roles may also cause tensions within the healthcare team, which may have implications for team working. This may stem from how the dietitians view themselves and how other team members perceive them. All the dietitians had a professional identity as an expert and wanted to use their expertise for the care of patients. However, if others did not perceive the dietitian as an expert, they may not accept the dietitian within these roles and may only use them as a technician. If the varied roles that dietitians undertake are not recognised by other team members, their view may not be sought and their voice may not be heard. The phenomenon of 'Wanting to be heard' will be explored in the next chapter.

Chapter 6: Wanting to be heard.

6.1 Introduction

In the last chapter I explored the varied roles and skills that dietitians described as part of their lived experience of involvement in decision-making about artificial nutrition and hydration (ANH). The roles were varied, but they were all considered important for decision-making and patient care. I also illuminated some of the tensions within these roles, for example, that dietitians may see themselves as experts. However, because some decisions were made without their involvement, they acted more as a technician to implement the decisions of others. The participants' professional identity was one of an expert, they wished to be recognised as an expert and be involved in decisions, and they wanted their view to be heard during the decision-making process. As experts in nutrition, dietitians being heard is important for best patient care, as well as for professional practice and job satisfaction. This chapter will now describe the dietitians' lived experience of trying to be involved in decisions through the phenomenon of 'Wanting to be heard'.

'Wanting to be heard' covers the range of experiences from appearing to be heard during discussions and having an involvement in decision-making through to appearing not to have an influence or be heard during decision-making. All dietitians wanted to inform decision-making, but some dietitians in some situations felt that they were not heard. The majority of dietitians expressed that they were not heard from time to time. Often this was because a decision was made to feed a patient before a referral to

the dietitian was made. This was a common issue for all the acute care dietitians, but it was only expressed as a problem when they believed that feeding was inappropriate. The emotional effects of these experiences will be considered in the remaining findings chapter.

6.2 Trying to be heard

Many dietitians reported trying to be involved in decisions related to ANH. As described in the last chapter, sometimes this was described as a battle. The data suggested that all dietitians believed that they had an expert role to play: that they wanted to be involved in decisions, to contribute to the debate, and to give their opinion. They seemed to want their view to be heard and respected, because they believed that they had knowledge and skills which would inform decision-making. Giving their view did not necessarily mean they believed that their opinion must be followed. They accepted that their opinion may not be adopted, but the important factor for them seemed to be having a voice, and being heard. This meant having a 'seat at the table' with others and being included in discussions about decisions.

'I suppose I, like today, on the ward round I just had to say, "She hasn't had any nutrition now for four days, what is the plan for this patient?"...So it's just having the confidence almost to bring it to a team's attention, which can be quite daunting as a band five...Luckily, the consultant's really friendly so he did go through all the reasons why he wouldn't do it at the moment...'

P7, junior acute care dietitian

'So say we got a referral...for a NG feed and we'd go down and the nurses say, "Oh yeah, the doctors mentioned feeding this morning" and the nurses say, "We're going to put the tube down this afternoon." Then we say, "Is the patient aware?" "No, they don't know anything about it." "Are the family aware?" The nurses might have just gone ahead a bit quick. And that might be when we say, "Okay, hold on for now, we'll speak to the consultant."'

P13, senior acute care dietitian

'They're [the doctors] normally very receptive to your opinion and they will listen to you. But it doesn't mean they are going to do something about it. But they will listen to you and take it into account...My opinion has been voiced.'

P12, senior acute care dietitian

'Well, [sigh] you'll have an opinion from a professional point of view and a clinical point of view. But it's always going to be tinged with how you feel personally. Erm, which you've always got to be open to, the fact that although you need to put it [an opinion] forward it may not be the best way for that patient. It's up to the whole team to decide what's best for the patient. Not just the individual.'

P12, senior acute care dietitian

For these dietitians, being heard in the team discussion seemed to be key to their experiences. Dietitian P12 appeared to believe that professionally she needed to give an opinion, but she had an awareness that her personal views might influence her recommendations. She felt that group

discussion was important to enable the whole team to decide what was best for the patient rather than an individual making a decision which might be influenced by personal values and beliefs. Taper and Hockin (1996) noted that religion or spirituality influenced Canadian dietitians' attitudes about the provision of ANH, and Seale (2010) and Wolenberg *et al.* (2013) noted that doctors' personal values and beliefs do influence their decisions. Within this research one participant believed that doctors' personal beliefs influenced decisions about ANH:

'I've certainly come across numerous instances where I think the doctors' own personal opinions influence their decisions...we've certainly come across doctors where [pause] they've got quite strong personal beliefs, religious beliefs, and you can see it influencing their decisions. They are very pro doing anything at all costs.'

P15, senior acute care dietitian

About a quarter of the dietitians described using different tactics to try to be heard during decision-making. Many dietitians suggested that they used their judgement to decide on which approach might be the most influential for any given situation.

'We have one consultant that if you presented him with the numbers that works quite well. And if you talk him through, you know, this is their requirements, this is what they need, this is why we need it, he does quite well with those...We have another consultant that if we put it in terms of rehab, physical, you know,

sort of actually being able to get a patient out of hospital again he's more likely to say yes.'

P16, senior acute care dietitian

This dietitian knew her team, so appeared to be able to pick the correct approach for the different consultants she worked with. She said:

'...you also get to know the consultants and you get to know the different approaches as to how you can then try and persuade them.'

P16, senior acute care dietitian

For some, a tactical approach meant by-passing the more junior doctors and targeting more senior doctors for a decision. A face-to-face discussion rather than communicating via the medical notes was also perceived to be a positive tactic to adopt. Some described how, if the registrar was in agreement with the dietitian, it would positively influence the consultant to agree with the dietitian's plan. Others believed that they needed to enlist a consultant to act on their behalf to influence a decision. These tactics were described by the following two dietitians:

'I have to admit with the ones that we've had recently actually going, missing junior members of the doctors out and going straight for registrar and consultant has actually got us to where we needed to be.'

P16, senior acute care dietitian

'Fortunately, our palliative care consultant who's just come on board is going to take that on and try and resolve that. And one of the issues is that the radiologist won't communicate with anybody else but another consultant.'

P4, senior community dietitian

These quotes suggest that there may be hierarchies in action. It appears that these dietitians are aware of these hierarchies, with one using it to her advantage by going to more senior staff, although the other felt disadvantaged by the hierarchy.

Dietitians trying to be heard by patients was also in evidence in some dietitians' accounts. One dietitian described picking the time to speak to patients when they were likely to be more receptive to advice, for example, waiting until a patient had asked to see a dietitian and being mindful not to push patients too much as it might be counterproductive:

'I introduced myself, just as a very initial. I didn't really need to see him...I just used the opportunity of that. And that's the sort of thing I'd do. I'd try and sort of wheedle my way in gradually, not pushy. And I think the patients still can be a little bit frightened by the dietitian or the thought of the dietitian, so I gradually wheedle my way in really.'

P9, senior acute care dietitian

This dietitian appeared to believe that seeing a patient without having first built up a relationship might not be as effective as waiting until a relationship with a patient had developed. Her tactic was to get to know the patient before advice was needed, which also suggests that she used her clinical experience to identify patients that might require advice in the future. Although many dietitians appeared to use tactics to negotiate with patients, the dietitians also appreciated that the patient could refuse treatment and could, at times, not adhere to a treatment plan.

Dietitians using different approaches or tactics as a means of influencing decision-making has not been noted in UK or international literature before. However, being able to use different tactics in different situations may contribute to a dietitian's voice being heard during decision-making.

Contrasting experiences were described when dietitians did not believe that their expertise was acknowledged, which resulted in the dietitians feeling frustrated and undermined. These and other emotions will be explored in the next chapter. Many seemed to believe that once the doctor had made up their mind, the dietitians' opinion did not count and the doctor would not change their decision. Many dietitians appeared to feel this could have a negative effect on patient care.

'Oncologists pose a bit more of a problem...And they very much believe in one thing and one thing only. So again, one oncologist believes that pump training and pump feeding patients seriously puts them back...I think it's just as acceptable a method as bolus

feeding...It makes me feel quite frustrated and I feel quite angry inside. But not angry because he's not listening to me, but angry because he's not doing what is best for the patient. So it's like it doesn't matter that he's not listening to me but it's like giving the patient the option. If the patient doesn't have all the information how can they make an informed choice? And I feel angry for the patient because they're not getting the opportunity or the choice.'

P14, junior acute care dietitian

'You can come in all guns blazing when you're new in post and think, "No no no! It can't be TPN [Total Parenteral Nutrition], all the risks involved". But you just know to leave it, because it just isn't, people have tried and you're not going to change them.'

P10, senior acute care dietitian

'The doctors had already made up their mind that they were putting a PEG in. And at the end of the day their decision is final. And sometimes you feel like [sigh], I'm not sure I agree with that, but at the end of the day they make the decision...But you don't want to think that you've caused harm, to cause it [death] to happen sooner than it needs to be naturally. I don't know. Or whether you're preserving life that's not meant to be there. It is hard, it is really hard...sometimes it does make you feel down and sad because you're just like, am I doing the right thing? I argued my viewpoint and said, "Oh have you considered this factor or that factor?" but at the end of that day the decision does come down to them.'

P1, junior acute care dietitian

These dietitians seemed to feel powerless to influence the doctor's opinion about clinical practice suggesting that they were not viewed as experts. They appeared to believe that they were not being listened to or respected.

A belief that the need for nutrition support was being ignored by other healthcare professionals was common. Many dietitians appeared to believe that nutrition and dietetics did not always have a high profile; that their clinical opinion on nutrition support was not important and there was a lack of respect for their view.

'I do think it's [nutrition] low down on the priority list for the Trust. I don't just think it's the Trust, I think it's, erm, I think it's a NHS wide thing. The 'Still hungry to be heard' documents came out and that didn't get a lot of press, I was surprised...So I think as a rule, unless it's the bad stories, we don't get to hear a lot about nutrition.'

P5, junior acute care dietitian

'Whereas the other consultant doesn't do anything with nutrition. He doesn't refer patients when he should do. He doesn't even mention nutrition in his plan or anything like that.'

P7, junior acute care dietitian

'...you feel as if they brush you aside sometimes, as if your opinions are not very important.'

P5, junior acute care dietitian

'I feel undermined...what's the point of me being here with this profession?'

P11, senior acute care dietitian

A lack of trust seemed to be the main reason why the following dietitian felt that her voice was not heard and that her opinion did not count. She believed that this was the only credible explanation for the team not following her advice. She said:

‘Well first of all I thought, “Have they just not read my entries?” Because they were clear, but I think there was also a little bit of a lack of trust...[that] I didn’t really know enough to be able to make that decision...‘Cos I couldn’t see any other reason why, when as a professional, I’d documented that he was absolutely fine. I couldn’t see any reason why they went down a completely different route that I’d never recommended. I just couldn’t see any other reason why. It had to be that they either didn’t read my entry, which is possible, or they didn’t believe what I had written.’

P2, junior acute care dietitian

This dietitian had documented her assessment and recommendation in the medical notes, that a patient’s oral intake was adequate and he did not need a PEG, but it appeared that the doctors took no account of this. Her opinion did not seem to count and she was not being heard. This lack of trust impacted on the ability of this dietitian to act in her professional role.

As suggested in the previous chapter in the section on advocacy, some dietitians seemed to believe that the profession of dietetics needed to be promoted in order to be heard. The profession of dietetics and individual dietitians needed to be more vocal about the role of the dietitian, for it to

be better understood in order for dietitians to be involved in decision-making. In reference to the event described, where doctors believed that a PEG was indicated but the dietitian did not agree, the dietitian said:

'...the nutrition bit they [the doctors] didn't understand it. And it was stepping outside of what they understood. And the panic button was hit even though they had somebody there [the dietitian]...But again I think they didn't really realise what we did. Which I think is a dietetic problem. We really need to promote ourselves...I think it's all very easy to say, "Oh they don't realise what we do." We need to tell them! I think as a profession or individually just chipping away at it and influencing. And it will just become ingrained then, won't it... Just understand what we do!'

P2, junior acute care dietitian

'...hospitals don't see nutrition as important I don't think...See I've often thought, no I don't think they see it as important and I don't think they see dietitians as important. But then that may be because we haven't shouted loud enough. So it's very well saying, "Oh well, they just don't see it as important as what we do at the moment," we make them aware of it...it should be accepted that we're specialist in that field.'

P2, junior acute care dietitian

Another dietitian also expressed this view:

'But it just doesn't happen [early ANH] in practice. That's not my experience of it happening in practice. I think if you've got a really

good stroke service set up then great. But I think we need to be a lot more vocal about that as well. I think we need to be more, sort of, in the faces of the stroke team. It's written that we should be a part of it, and I think we just need to push to make sure that we are.'

P5, junior acute care dietitian

These experiences of being unsuccessful in being heard during decision-making, and dietitians' opinions being dismissed, raise interesting questions about dietetics as a profession. As some dietitians were heard, it suggests that it was not the whole profession of dietetics which is being dismissed. Being heard is an important part of dietitians' professionalism, therefore aspects of the described experiences which promoted being heard will now be analysed.

6.3 Being known

Being heard by the wider multi-disciplinary team was facilitated by being known. Many dietitians described how being known by the team meant that it was easier to work with them, and they could develop positive relationships, so they were more likely to be heard. Canadian dietitians surveyed by Szeto *et al.* (2014) also felt that positive relationships with doctors enabled their involvement in decision-making about PEG to be more extensive. However, this has not been noted in UK dietetics before.

'...generally that [team working] works fine. We each know what each of us is doing, what the score is, and we know what questions to ask of what people. I think it probably just comes from a team

that you're used to working with. You know, we know each other...It's usually very good.'

P9, senior acute care dietitian

'Discharge planning, and now because I'm there, he'll say, "[dietitian's name] nutrition? Is PEG [Percutaneous endoscopic gastrostomy] feeding established?" That kind of thing, you know, everybody gets their say. And yeah, I think they're a pretty good experience really...Yeah, I like that [being recognised in the role]. That feels good.'

P11, senior acute care dietitian

'So going around on ward round not only saves my time, but it's also they can, they can be more familiar with me. So I'm on the ward they can, they know who I am...After I explained what the plan was and I was doing, they were absolutely fine. They didn't even question it.'

P7, junior acute care dietitian

When dietitians were not known by *all* members of the team, it seemed that relationships were more difficult and problems arose. This was clearly illustrated by one dietitian who was well known by nurses and other healthcare professionals in a psychiatric setting. She had worked closely with these team members, and as they accepted her as interested and knowledgeable about the patient group, referrals had increased. However, she was not known as well by the psychiatrist who worked on the unit.

This dietitian appeared to believe that this was the reason for the psychiatrist not accepting her view that a patient she was treating did not need a PEG. The rest of the team accepted her assessment that the PEG was unnecessary and supported her.

'It was nice that they [the ward] were so supportive. And they believed it [the dietitian's view]. I just had to convince the psychiatrist...looking back when I first started there, we didn't get many referrals from those wards. And now we do. And their attitude to me had changed, to dietitians, to what we do. And I think well maybe that's because I've worked closely with them [the ward], but I don't see the psychiatrist so often.'

P2, junior acute care dietitian

This quote powerfully illustrates how those who make the ultimate decision needed to know the dietitian, and that while knowing part of the team was beneficial, the dietitian needed to be known by the whole team in order to be heard.

For many dietitians 'being known' developed over time through having a presence in a clinical setting. By being present, many dietitians felt it was easier to develop relationships with the team and increase the profile of dietetics and nutrition. This appeared to be a virtuous circle: the more they were present and seen, the more they were asked for an opinion and were listened to; the more they gave an opinion and were listened to, the more they became known and so on.

'I can remember the first couple of times I went over there and I didn't feel included at all...I certainly didn't feel as welcome when I first went. It wasn't until they almost realised I was one of them that that suddenly changed...I was taken into the fold. "Oh, you've got a background haven't you", and, "It's not what we expected." So I think there was a difference. But it took me a long time, it took me six months to build that up I think. And to get it to the point it was at then. It certainly wasn't an instant.'

P2, junior acute care dietitian

'I think it's just an oversight sometimes. If they see you, they point it [the feed] out to you.'

P5, junior acute care dietitian

'My first assessment was this patient needs a NG feed. She consented. Within the hour the tube was placed, position was checked, and we started feeding. And that tends to happen quite a lot on that ward...[because] it's a mixture of the consultants who are used to dietetic input so they're used to us seeing these patients and fighting for it if we need to...So I don't have to fight so very much which is nice.'

P5, junior acute care dietitian

Being known in order to be heard suggests that relationships are important.

Dietitians who did not have enough involvement with the team, or if the dietitian did not have a relationship with the team, did not seem to be

known or heard. Some dietitians seemed to feel that not being known by the team or ward meant that they were excluded from decision-making.

'But if I was doing my general [work] which is all over the hospital, I don't really know any of the other teams...and a lot of consultants don't actually have much respect for dietitians either. They just...do what they want to do and don't really take our opinion into account...I think they want to do their plan and then when you bring up something else into it, they think, "Oh no, we'll not bother with that at the moment, we'll just continue what we want to do."...[Which makes me feel] that I'm not really a member of the team and my opinion isn't really accounted for.'

P7, junior acute care dietitian

This dietitian appeared to believe that her opinion was not heard because she was not accepted as a team member, and that the team did not respect or value her view. The team had made their mind up about the treatment plan and they were not going to be swayed by her professional opinion.

Within a community setting, not being known by the team influenced the experience of 'trying to be heard' during decisions, as the usual contacts and networks were not present. This was so important for one dietitian that she jokingly suggested that being known and having relationships with other staff was one of the reasons why she stayed in her job.

'But one of the issues for this lady is that she's a cross boundary lady...[which] means that I...know the minority rather than the majority of people involved. So I don't have anything to do with the neurologist that she goes to see. I don't have any connections with the hospital or the palliative care services on that side of the border. So the only ones I think on our side of the border are myself and the speech and language therapist, and we have quite a good working relationship. And one of the issues is knowing who to contact and how to contact them. Even if you get a name you don't know where they are based, you haven't got a phone number. And I don't have a clear idea of who else is involved in her care at the moment.'

P4, senior community dietitian

'I think when you build up relationships with people that you work with it gets easier and that's one of the things that keeps me where I am because I don't want to have to go through all that again [laugh].'

P4, senior community dietitian

The dietitians who were not heard during decision-making, many of whom were junior dietitians, discussed issues of time and workload as barriers to 'being known' by the team. These junior dietitians seemed to feel that they were unable to attend team meetings, so were not able to have a presence, so were less likely to be known or be heard. Other dietitians

described the difficulty they had in communicating with teams, because they did not know the team and the team did not know them.

'I think our stroke ward shouldn't be covered by a band five; it's a band six post. Because there's not enough MDT [multi-disciplinary team] working, there's not enough time to actually do it with a band five case load.'

P2, junior acute care dietitian

'There's [a multi-disciplinary team meeting] on a Monday and Thursday, but I don't get a chance to go at the acute side, but I go to the [name of hospital] one...But, erm, I'm only there three sessions per week so if I'm there for nearly the whole [multi-disciplinary team meeting], I'm missing out on patients.'

P1, junior acute care dietitian

'...I don't really know any of the other teams. Sometimes like approaching them [consultants] can be a bit daunting.'

P7, junior acute care dietitian

'It's hard as well when you go onto a ward that's not your own because you haven't developed relationships with people.'

P1, junior acute care dietitian

For these dietitians, time and work pressures leading to a lack of attendance at ward rounds or the feeling of being daunted by senior doctors all contributed to not having a presence and so not being known so making it harder to be heard.

6.4 Making a difference

Having a presence and being known to the team seemed to facilitate being heard, but perhaps an even more important aspect of experiences was demonstrating that you can make a difference to patient care. The interviewed dietitians seemed to believe that when they were seen to make a difference to patient care, the team then started to trust them and value their opinion. For many dietitians it was making a difference to care and clinical outcomes which helped the team to be more receptive to them. For these dietitians, making a difference was related to improving clinical outcomes, such as patients tolerating ANH, successfully dealing with problems related to ANH (such as diarrhoea), and improving patients' rehabilitation potential by improving their nutritional status.

'...we've shown them [the doctors], we've been able to give them case studies of if this, you know, if you don't feed the patient, this is what happens and this is how much weight they lose. And I think because we've had some quite severe weight loss patients, when I first started in trauma, in a way that's worked in my favour in order to say, right we want to feed these patients. You want to get them out, you want to get them mobilising...cos it's not just the initial injury, it's the rehab afterwards. And, erm, when I first started we had a couple of real problem patients, just in terms of absorbing feed and tolerating feed. So in a way, because they can see what you can do, it's made them much more receptive.'

P16, senior acute care dietitian

'And it's interesting, because certainly over the years of being in this role [dietitian in the nutrition team] we have seen practice change as they've got more confident of us and the fact that we're not letting them [place unnecessary PEGs] or we're challenging them.'

P15, senior acute care dietitian

Another dietitian outlined how being involved with staff and supporting them enabled her to make a difference to patient care. This dietitian showed that she had made a difference, so she was invited to a planning meeting which enabled her to be heard:

'So in that meeting we touched on the possibility of a PEG. And I said, "Well you won't accept him back here [to the psychiatric hospital] with it"...And she [the psychiatrist] said, "Well I haven't got a problem with it." And the ward manager said, "Well I haven't got a problem with it 'cos now we're really well supported." And he's now booked for his PEG on Thursday...'

P2, junior acute care dietitian

By showing that dietitians can make a difference to care through their advice and by supporting the rest of the team, these dietitians were able to influence patient care, fulfil their professional role, and were heard. While being known and having a presence has been noted in the dietetics literature as being beneficial (Thoresen *et al.*, 2008; Mitchell *et al.*, 2012),

that making a difference to care facilitated involvement in decision-making by enabling dietitians to be heard has not been noted before now.

6.5 Speaking up

As discussed in the last chapter, many dietitians had an advocacy role, that is, when they tried to be heard and speak up for their patients' wishes. They believed that they understood what their patient might have wanted as they appeared to understand their patients' values and wishes, and what was important for them. Many dietitians seemed to believe that they had the authority to speak up on behalf of their patient because of their perceived expertise, that they had taken time to get to know their patient directly or via their family or carer, and that they were trusted by the patient and had built up a relationship with them.

'But when you first meet them...you haven't got a rapport with them to be able to talk to them frankly. So you have to build that up, that can be quite difficult...Until you get to know them and know what they will be able to handle and what information you can pass on to them and they will be to, you know, take that in and deal with it...it's a discussion that we have at our meetings, "Have end-of-life issues been discussed and has it been documented?"...because tube feeding is one of the things that they want to make a decision about that.'

P4, senior community dietitian

Developing trusting relationships appeared to be an important part of the lived experience which enabled some dietitians to speak up. For one

dietitian this experience included receiving unique clinical information from a patient because the dietitian believed that the patient trusted her. For another dietitian, that her patient seemed to put his trust in her motivated her to act in order not to break his trust and to speak up. Both these dietitians appeared to have the authority to speak up and be heard:

'...she felt that she could trust me...she felt that she could tell me more than she could tell the doctors.'

P7, junior acute care dietitian

'He still refused to drink or have anything to eat. So we prescribed the supplements but I arranged it with fluids as well, so it was all prescribeable. If it was prescribed he would take it...and then was called...to say they were going to put a PEG in...I firmly objected. Because he was having his supplements, he'd agreed to all of these plans, it was a collaborative process between us, and he was doing fine. And I just thought it's just wrong that after all of that, we're then saying that actually we're...going to force feed you, even though there's not a problem at all...I just felt that it was such an abuse of his trust.'

P2, junior acute care dietitian

Some dietitians believed that they should speak up when they thought feeding was inappropriate. This might be in relation to initiating a feed, continuing with a feed when they thought patients had a poor quality of life, or withdrawing a feed, which might mean end-of-life decisions. They believed that it was their role to highlight this difficult issue to the team to

protect their patients. They spoke up when they had concerns that feeding might be seen as an easy way of providing fluid and medications by nurses and doctors:

'I just wrote in the medical notes that at this stage I don't think it's appropriate to NG [nasogastric] feed him because of his poor prognosis and the deterioration in him in the last few days.'

P1, junior acute care dietitian

'But you went to see this patient, and she was skin and bones. And she'd got a very, very poor prognosis...It wasn't appropriate because [pause] death was imminent with her...I actually went and spoke to the registrar and said, "Is it appropriate?" Because there's lots of other things happening at that point...And it did get stopped at that point...I...said, "I'm not sure this [feeding] is appropriate with this patient." And he [doctor] looked at it and said, "No it's not".'

P12, senior acute care dietitian

'It [ANH] sometimes is looked on as an easy option I think. Which is fine, because they've [doctors] got more important, others things to think about. That's what we're there to do, isn't it. That's what we're there to look at...And that was something that I said to the consultant every time I saw him [is this right?]. And...it ended up that he would smirk at me and say..."You're going to say it, aren't you?"'

P13, senior acute care dietitian

Some dietitians recounted how they spoke up about issues of consent. They challenged the teams and spoke up on behalf of their patients where they were concerned that consent had not been obtained:

'...[the patient] said, "Now what's this for?" [Indicating something on the cheek.] And it worries me that it's [a tube] actually been put down without somebody really understanding what it is...if I come across that I will document it, but I'd also speak to the medical staff and say, "Look, they don't know why that tube's down". And I make sure that when they're putting down future tubes, that they are actually explaining it to the patients...And some of them [the doctors] are, "Oh yes I hadn't thought of that"... One was very defensive, "Well this patient needs it". And I said, "Yes they need it, but if they had the capacity to be able to consent...you need to explain what it is that you're actually doing, and why you're doing it".'

P16, senior acute care dietitian

'We went to see the patient and the NG tube hadn't actually been passed. And from reading the patient's notes, the medical notes, we could see that he had quite a poor prognosis really. And that led us to wonder why the tube was being passed. So we got one of the doctors and said, "Why is this tube being passed?"... He'd [the patient] been refusing the NG tube. We were, "We're not going to a regimen because obviously he doesn't want it".'

P14, junior acute care dietitian

It is interesting that many dietitians spoke up about the appropriateness of feeding, as it implies that these dietitians were not just thinking about ANH as fluid and fuel for the body, but of the ethical aspects as well. It might be expected that dietitians would promote feeding as they are trained to detect, treat, and prevent malnutrition. However, many of these dietitians took a more holistic view, showing their professionalism, and both the courage to speak up and ethical sensitivity. They seemed to show that it might not be right to feed some patients in certain situations; for example, when a patient had a poor prognosis or a poor quality of life, if the feed was considered futile, or if a patient had expressed the view that they did not wish to receive ANH.

The ability to challenge and speak up in a face-to-face setting is important, as it has been shown to have a greater influence on doctors implementing dietitian's recommendations compared to written requests (Skipper *et al.*, 1994). Indeed, face-to-face communication has been shown to enhance collegial working across a range of disciplines compared to written communication (Gotlib Conn *et al.*, 2012).

While many dietitians spoke up, not all did. This will be described in the next chapter in section 7.7 on moral distress.

6.6 Silenced

To be involved in decision-making, a certain amount of clinical information is needed and ideally the dietitian needs to be included in the discussions.

This information includes the medical plan for the patient. Much of this information can be collected from the medical notes or from multi-disciplinary team discussions. Not having the full information can be a barrier to decision-making, as it cannot be included in discussions about decisions. Many dietitians in my study felt this was the case; they did not have all the information that they needed and were not included in important discussions. This meant that it was difficult to form an opinion about if ANH was indicated and so to meaningfully contribute to the discussion; effectively they were silenced.

Dietitians expressed the view that they needed to know what the medical plan was for patients, in order for the dietetic plan for nutrition support to fit with it. In cases where the team were actively treating the patient, ANH should be provided; however, if the team were not actively treating, then nutrition support would be less aggressive and ANH may not be appropriate. One dietitian felt that once the medical plan was clear it was easy for the dietetic plan to dovetail with that. However, having a clear view of the plan was sometimes not easy:

'And once you often know the medical plan, it makes the dietetic plan quite easy to be able to kind of slot in to that...Within the trauma teams, you have a lot of personalities and we have a big MDT [Multi-Disciplinary Team] meeting where we go through every single patient...you can have a 20-minute discussion about a patient, can come out and think, "I don't know what you plan to do with that person." So from that point of view that can be, erm,

challenging... Sometimes that's clear, sometimes that's not quite so clear. Sometimes you come out and think, "Ah no idea".'

P16, senior acute care dietitian

Many dietitians revealed that the difficulty they had in obtaining full information was due to poor medical notes. Dietitians described the information in medical notes to be:

'... a bit sparse' P6, senior community dietitian

'... a nightmare' P3, senior community dietitian

'... not often ideal because you don't always get the full picture'

P8, senior community dietitian

Although the dietitians expressed the feeling of not having enough information for them to be heard during decision-making, they did not express this in terms of a debilitate act to exclude them from the process.

Some dietitians expressed concerns that they had not been involved in the discussions about ANH which took place with the family. Some dietitians appeared to believe that doctors were pressured or coerced into feeding some patients because this was what the patient's family wanted. In some cases dietitians appeared to believe that doctors did not think feeding was appropriate, but the doctors had agreed to it because of family pressure. In some cases it seemed that the doctors were expecting a 'technician' dietitian to provide the feeding regimen rather than an 'expert' to be

involved in discussions and decision-making. It seemed that in some cases the family's voice was more influential than the dietitian's voice. Some expressed concerns that when they were not included in discussions, what they perceived to be the best decision was not made.

'I was quite surprised...it wasn't necessarily that the medical team wanted the feed, it was more the family pushing for it. And so the medical team was just sort of going along with it...It sounded like he [doctor] was going along with whatever the family wanted...he didn't stop to ask what do we think about it, did we feel it was appropriate. Or even why we were asking the sort of questions...I think he just expected us to come down and do the feed and then go home... And the reason the doctor gave for them passing the tube was because the family wanted it.'

P14, junior acute care dietitian

'If you come along, NGs actually been put in, at the doctor's suggestion. I don't think it's appropriate; I've got to provide a regimen anyway. It gets you annoyed, it gets you angry. You think, "I wish I'd been involved before they'd actually put that tube down." There's no way of knowing until they're referred though...It can be that the family been very pushy and they want their relative fed no matter what. And the doctor has caved into that pressure instead of standing up to them and saying, "This is what's going on, it's not, [pause] it's not fair to the patient to proceed with this".'

P11, senior acute care dietitian

'It's just, erm, [pause] the consultant will often discuss things with the family but we're not involved in that, which worries me a little bit as well...and they're [the family] speaking on behalf of somebody else. We're doing it in the best interest of the patient, but we've never actually spoken to the patient. So it's the best interest of what we think the patient needs because of what their family said...I think...[we should be involved in]...the discussions because...the consultants ask us about PEG feeding long term, so I don't think they know a lot about it. Which worries me because when they're talking to families they're not actually giving all the information...'

P2, junior acute care dietitian

'...with the group of doctors we have at the minute, it's that we have a lot of tubes put in people that if you'd got to see them first and you got to them before the doctor had, you wouldn't have suggested NG feeding for them.'

P16, senior acute care dietitian

The lived experiences these dietitians described suggest that they were concerned that their patients may not be getting what they believed was the right treatment, and that the wrong decisions might have been made because of a lack of their input.

Most of the dietitians' accounts of family pressure to feed appeared to be negative, as many believed that feeding was not appropriate, and that families pushed for a decision based on what they wanted (ANH to be

started) rather than the decision being made based on what their family member might have wanted (not to extend their life). One dietitian speculated if some of her patients who received ANH would really have wanted it:

'I don't think it changed her overall survival, whether she'd thank me for having that NG tube down I don't know. It does, it's always made me wonder if she didn't have a family that pushed she probably won't have ended up with that tube.'

P16, senior acute care dietitian

'But that was all instigated by family, which is one of those ones and I always look back and think...if we'd done it as what we would [normally] have done, we wouldn't have PEGed her, we wouldn't have NGed her. I don't think she'd be overly impressed with the PEG tube. She kind of came across as the sort of person that wouldn't have wanted something like that. But in terms of family it meant that she was then able to spend some time with her family at home before she passed away. That was quite family driven.'

P16, senior acute care dietitian

Kuehlmeyer *et al.* (2012) noted in their German qualitative research of various families' involvement in decisions made about patients in a vegetative state that the family's decisions were to continue feeding, even though it might not be what their family member would want.

It appears that for many dietitians, they were 'silenced' by not having full clinical information, partly due to issues with medical notes, partly due to

not attending multi-disciplinary team meetings, and partly because decisions were made without them, all of which led to not knowing the plan for the patient. Not having the full team at multi-disciplinary meetings can be problematic as Christensen suggests that it is only when teams integrate different pieces of clinical information that the full clinical picture emerges (Christensen and Abbott, 2000). It is not clear from the dietitians' accounts if the lack of information sharing from other team members was deliberate or as a result of the above factors. It does raise issues of role perception and professionalism. If the doctors do not perceive the dietitians as having a role in decision-making, they would not be invited into such discussions. What these experiences also seem to suggest is that without the full information it is difficult to understand why certain decisions are made. If dietitians do not understand this, they may feel troubled by it. This will be explored in the next findings chapter.

6.7 Conclusion

This chapter has highlighted dietitians' desires to be heard during multi-disciplinary team discussions and during the decision-making processes. It has also highlighted the importance for dietitians of being heard and respected during the decision-making process. These findings are complex and contradictory, as sometimes dietitians were heard, had an influence, and were respected, but at other times they felt they were not respected or heard. At times some dietitians appeared to be powerless to influence decisions.

The dietitians who were heard and respected were known to the team by having a presence and by being able to show that their contribution made a difference to patient care. Being known by the team and demonstrating a clinical benefit led to trust in the dietitian and helped to facilitate team working and decision-making. The professional skills of communication, team working, building relationships, and confidence plus experience were all important for this. Many dietitians appeared to demonstrate expert power in these situations, and their expertise was recognised by others affording them some power. For many dietitians successful involvement did not necessarily mean having their view accepted and adopted, but it appeared to mean having their view heard and respected. For them the important aspect appeared to be being heard.

While some dietitians were being heard, there are many situations where this was not the case. They did not have a voice because decisions were already made without consultation with them or they did not have all the information they needed to contribute to discussions. Many believed that their opinion did not count when decisions were made about ANH.

Professionally, this was difficult and challenging for them. When dietitians felt uncomfortable with the decision made, they expressed their lack of input as a problem. When they were not heard, some felt frustrated, undermined, and dissatisfied, suggesting powerlessness. Some dietitians believed that this was due to a lack of trust in them, or a lack of belief in the benefit of nutrition support.

A lack of influence and respect for one's opinion can result in feeling demotivated and suffering burnout. It has implications for the professional status of dietetics. This feeling of powerlessness had an emotional cost for some. The emotions related to these and other types of situations and how my participants responded to them will be explored in the next chapter.

Chapter 7: The emotional roller coaster

7.1 Introduction

In the last two findings chapters I have illuminated the lived experience of dietitians' involvement in decisions within artificial nutrition and hydration (ANH) by exploring the varied roles that dietitians undertake and revealed their desire to be heard and involved in decision-making. Some of the tensions the dietitians experienced have also been revealed; for example, dietitians may see themselves as experts, but others may perceive them to be technicians who implement others' decisions. The varied experiences of trying to be heard during decision-making have also been revealed. For many dietitians successful involvement in decision-making meant their opinion was heard and respected.

These previous findings chapters have alluded to some of the emotions dietitians experience, such as the positive feelings of being recognised and accepted as an expert. Other emotions included feeling uncomfortable, frustrated, undermined, and dissatisfied, which were experienced when the dietitians were not respected or not heard during decisions, especially if they did not agree with the decision made. It might be expected that there will be an emotional element to the work of a dietitian as it includes interpersonal face-to-face contact with patients and relatives and involvement with ANH, both of which have the potential to be emotive (Monturo, 2009; Gingras *et al.*, 2010). In this chapter I will further explore the emotional experiences dietitians described when involved with ANH and how they responded to these experiences.

Emotional experiences appeared to be a part of the everyday lived experience of dietitians. Even within one situation, varied and complex emotional experiences were described:

'I had such a range of emotions about speaking to her...I just felt really, really sad for her...it was heart-breaking...you kind of think, "God, it will be an emotional roller coaster for us as a team".'

P15, senior acute care dietitian

This dietitian described how she felt sad, relieved, confident, concerned, and apprehensive when speaking to a palliative care patient about nutrition support. Contact with patients is likely to be emotive from time to time, but it was a surprise to hear so many emotionally laden accounts from my participants, especially related to their normal everyday practice. While it was expected in difficult end-of-life situations, it was not expected in normal everyday practice and has not been reported by dietitians before.

The philosophical debates around emotions are complex, and there is much debate about theories of emotions, the differences and similarities between feelings and emotions, and the classification of emotions (Whiting, 2006; Slaby, 2008; Deonna and Teroni, 2012). As my interviews included a lot of emotional experiences, and as this research aimed to explore the experiences of being involved in decision-making, this chapter will focus on the emotional experiences described by my participants and how they responded to them.

The phenomenon of emotional experiences related to dietitians' involvement in decision-making regarding ANH did not stop at an emotional response. The interviews also revealed how dietitians responded to these emotions. Strong emotional experiences require coping strategies and support to enable healthcare professionals to fulfil their role, care for their patients, and avoid burnout. Therefore, this chapter will also discuss dietitians' lived experiences of responding to their emotions. I will explore how the dietitians' accounts revealed how they responded to their emotions during their clinical practice and during interactions with patients, relatives or carers, and other team members.

The emotional experiences that dietitians described included pride in doing a good job when they were acknowledged by others or they felt happy with the job they had done. They felt anger when decisions were made that they considered not in the patient's interests, or when their professional opinion was ignored. Guilt was expressed when patients suffered adverse consequences of ANH. Often dietitians felt unsure and uneasy about if a decision was right for their patient, and some appeared to experience moral distress. The experiences of responding to their emotions were varied. 'Don't show it' describes the hiding of true emotions by some dietitians. 'Keeping a distance' reveals the distancing from emotive situations that some dietitians undertook to protect themselves. 'Becoming desensitised' explores the way that some dietitians started to become a little hardened or blasé to emotional situations. Some dietitians responded to their emotions by 'Speaking out' about emotive situations.

Finally, some dietitians responded by seeking support, as illustrated in 'Needing support'.

7.2 Proud to do a good job

The phenomenon of 'proud to do a good job' was multifaceted. It relates to the emotional experiences of patient contact, but also of working in teams. The experience of feeling proud appears to be partly external to the dietitian: when others acknowledge the good job undertaken by dietitians, but also internally to the dietitian when they appeared to feel happy with the job they did.

All the dietitians described being committed to doing the best they could with respect to patient care. There was a feeling of being proud to do an important job and to be part of the profession of dietetics. They all believed that their care had positive effects for their patients and that they made a difference to care. Many dietitians talked of feeling valued and respected by their teams and feeling valued by their patients; this resulted in positive emotional experiences for them.

'...we have got a good team for progressive neurological [patients], and whether they've got a tube feed or not then I will see them, most of them anyway...That works much better...They get a much better experience and we often have very complimentary comments from the patients about the support that they feel they get, which is nice. [Laughter] It feels good [laughter] that it works well. And it

makes you feel proud that you actually work in a team that the patients get a lot from.'

P4, senior community dietitian

'And they've [staff on the wards] said it's the first time they've had a dietitian that's embraced the mental health...[which is] really nice.

It's nice because I am interested, I want to do the best.'

P2, junior acute care dietitian

These dietitians received the feedback from patients and colleagues: external praise to give them the sense of feeling they had done a good job. In other situations the feeling of pride came from the dietitian herself. There appeared to be a sense of internal feeling of pride because they were skilled and made a difference to patient care.

'You really feel like it's a part of treatment...So you do feel really included in that [nutrition support on a surgical ward] and what you're doing is important. And it's skilled as well...it's great.'

P2, junior acute care dietitian

'...within my role I do a lot of PEG counselling now, for someone going to have a PEG. It wasn't something I'd done before and I have hopefully taken it on quite carefully. But I have felt there was a need for that, rather than them going up to an outpatient appointment, not getting the information...I've enjoyed doing that role and I think it is a key role.'

P6, senior community dietitian

'Although the fact they'd reversed it, and I think in the notes they'd written the dietitian does not believe this is required. So it was definitely me, dietitian doesn't believe this. And that was documented so I thought well, they have actually listened to me as a professional...[I was] really chuffed!'

P2, junior acute care dietitian

These dietitians all appeared to be proud of the job they did and felt valued and respected. Reports of these experiences are lacking in the literature with UK dietitians.

7.3 Feeling angry

Many dietitians' emotional experiences were rooted in a deep concern for their patients to get what they believed was the most appropriate care. Dietitians seemed to feel angry when they believed that patients were not being treated as they thought they should be. They also felt angry when their professional skills were questioned in the care of their patient:

'[it makes me feel] pretty rubbish actually. You know, as though I don't know how to do my job. And I'm not really worthy of speaking to. And that [look of annoyance] makes me quite angry sometimes. And he [the consultant] quite dismissive of my concerns for patients...and that's an area I can't do anything about really. It pees me off [laughter]. Excuse my French. Yeah it really does.'

P4, senior community dietitian

'So it's like it doesn't matter that he's not listening to me but it's like giving the patient the option. If the patient doesn't have all the information how can they make an informed choice? And I feel angry for the patient because they're not getting the opportunity or the choice.'

P14, junior acute care dietitian

The anger experienced seems to be related to doctors being dismissive of the dietitians' concerns for their patients, together with the impression that the doctors were being dismissive of the dietitians as experts. For each of these dietitians the frustration and anger seem to have been rooted in a feeling that their patients would not be receiving what they believed to be the best care. The feeling of powerlessness expressed by P4 also seems to suggest that she was also angry with NHS hierarchies which affected her ability to influence patient care.

Feeling angry because of concerns about patient care was also highlighted by some dietitians when their treatment plans were questioned:

'...she [the hospital dietitian] just basically said, "Well why is she on this regimen?" And I was, "Excuse me?" [laugh] "Because that's the regimen that I calculated for her and it meets her requirements, full stop"...So it then just made me think that they were questioning the regimen that I had her on, which I think was absolutely fine for that patient. So I was annoyed. Because I thought, "Well, you don't even

know this patient. I've seen her regularly...And I know her and I know that she was fine on that regimen, so don't question me about it".'

P3, senior community dietitian

'I'm quite firm with what I say because it's delivered with a bit of conviction behind it as well. And I'm normally cross as well [laugh] so that normally helps...So I firmly objected. Because he was having his supplements, he'd agreed to all of these plans, it was a collaborative process between us, and he was doing fine...[I felt] Really cross [laugh]...And it still makes me cross, but I was disappointed as well...'

P2, junior acute care dietitian

The experiences of these two dietitians seemed to show their anger when their treatment plan, and so by implication their professional knowledge, was questioned. P3 seemed to know her patient well, and therefore believed that she knew what the best treatment plan was. P2's anger seemed to be rooted in the fact that her judgement as a dietitian was being questioned.

Others expressed their anger that other staff did not seem to take nutrition support seriously or that their colleagues did not know what was happening with their patients, overall suggesting poor patient care. One dietitian expressed her shock and anger that patients were not being helped to eat:

'Because it doesn't take five minutes for a nurse to sit and watch and see how his swallow is with those textures. But they're too busy, or they're understaffed. And that can be hard sometimes...And sometimes nurses go on their breaks when it's dinner time. And you're like, "Surely you should be on the ward to help the patients eat their food?" And it's just shocking...And to me nurses should be involved in all aspects of the patient care. You go to someone, "Oh what did so and so have to eat today?" "Oh I wasn't on shift" or, "I don't know, it wasn't passed on." And I hate that. You should know what's going on with your patient.'

P1, junior acute care dietitian

Feelings of anger were also expressed when implementing trust policies. One dietitian described the policy of assessing patient's suitability for the use of reusable versus single use syringes to be emotionally difficult, as she believed that it was wrong for her to assess how 'clean' the patient's home was. She seemed to feel that this was morally difficult, because she believed that the policy was for the benefit of the trust, not the patient:

'And we have to go though and assess to see whether a patient is hygienic enough to have reusable syringes. I think it's just awful...Attention seems to be transferring from a hospital environment to somebody's home...I don't like it, you know...I just think it looks like, "Oh well, we would let you have reusable syringes, but I'm afraid you'll have to put up with all these boxes mounting up in your very small one-bedroom flat because actually you're not

clean enough." I've got a real problem with that at the moment...I don't see we've got the right to do that just to cover ourselves. That's a big bane at the moment.'

P9, senior acute care dietitian

Feeling angry may be linked to some of the roles discussed in Chapter 5. If some dietitians believed that they are experts, they may not take kindly to their decisions being questioned. If the dietitian believed that they have been undertaking an advocacy role, again they may not be happy being questioned when they believed that they are acting on the patient's wishes.

Feeling angry due to concerns about patient care has been reported within healthcare settings among doctors and medical students (Johnston *et al.*, 2011; Monrouxe and Rees, 2012; Rushton *et al.*, 2013a), nurses (McCarthy and Deady, 2008; Restrepo and Pilgrim, 2011), and midwives (Hunter, 2005) but has not been reported within dietetics before.

7.4 It's my fault

The lived experience of 'it's my fault' relates to the feeling of guilt that some dietitians described. The feelings of guilt were related to the consequences of patients receiving ANH. Some consequences might be expected, for example, the side effects of ANH.

'I suppose there's a tendency to think that if something doesn't go to plan it's your fault and you've made something worse...someone's vomiting, diarrhoea, you think, hum, "Should I

have started it slower? Should I have tried them on this? Should I have done that? Should I have left it a bit?"...There is a tendency to think it was my feed that caused it.'

P9, senior acute care dietitian

The long-term effects of receiving ANH seemed to lead to feelings of guilt for some dietitians. These were expressed by some when patients were not able to go home with ANH and the dietitians felt responsible for splitting up a family. A belief that the provision of ANH meant patients did not die but lived with long-term disabilities, was the source of guilt for another dietitian. The quality of life of patients receiving ANH will be further considered in the next section.

'...so many times it's come to like a team meeting with the family. We're talking about plans for discharge and it's only then they're having to think about, "Oh, could we look after this at home?" Understandable - they're just thinking, "I want my relative home", but they have no idea about how much work that involves. And when you spring it on them at that stage, it's really hard for them to take. That possibility they can't have their relative home just because of this feeding tube. [and then] I feel awkward. I feel bad, I feel guilty like I've, just because I'm the dietitian, I'm involved in the feeding. I feel like I'm sort of splitting up this family, causing problems...'

P11, senior acute care dietitian

'...“92-year-old lady, swallows not brilliant, she's not eating that much, can we put an NG down?” And...you're like thinking, “Should a NG feed really go down?”...And this lady just wanted to go home...[but] she's too frail for a PEG...[so] she's got to go to a nursing home...And then, since being told that she's going to a nursing home she's deteriorated. And...the daughter was upset in the MDT [Multi-Disciplinary Team] meeting, I could feel myself welling up...was it wrong of us to NG her in the first place?...and I thought, “Oh she really wants to get home now”. So in a way I delayed it...it is quite sad really...I did cry all the way from [one hospital] all the way to [another hospital]. And I had to leave the hospital ward quickly because I thought I'm going to cry in front of these people soon.'

P1, junior acute care dietitian

'I do wonder how many of the people that we have fed maybe would have died a week later had we not fed them. We've doomed them to a life of chronic disability...To me I'm mortified when I attended a couple of nursing homes...And there were people with strong disabilities. And it was just horrendous.'

P2, junior acute care dietitian

Feeling responsible for negative consequences greatly troubled one dietitian who discussed how she was affected by a patient's death. She was deeply involved in the patient's care and took on a great deal of

responsibility for the patient, which seemed to contribute to her feeling of guilt:

‘And for this man everything that could go wrong went wrong. Not just the feeding tube, everything. And that for me was awful. And I cried and cried and cried. Not because he died but because of the way he died...and you try and go back and think, “Where could I have changed it? Where could I have done it differently?” And I think I did blame myself for a lot of what went wrong and I blamed my inexperience I think. Errm, and I did have to go and have some reflective sessions [laughter] with my manager and colleagues and things because I just felt awful about it...I felt it was all my fault.’

P4, senior community dietitian

While not all dietitians reported feelings of guilt, it has been reported in other health professionals (nurses, support workers, occupational therapists, physiotherapists, speech and language therapists) by Brazil *et al.* (2010). It has not been reported within dietetics before now.

7.5 The worry of trying to get it right

Dietitians described their worry and concern about the uncertainty around doing the right thing during their discussions of a number of different situations. These included making decisions for patients when it was not clear what the patient wanted, when they were unsure if tubes should be re-sited when they had become dislodged, and decisions to start or to continue ANH with patients whom they believed to have a poor quality of

life. During the interviews most dietitians described feeling unsure whether they were doing the right thing at some point.

7.5.1 Making decisions for others

Many dietitians expressed anxieties when trying to make the decisions for patients, often because they did not know what the patient wanted. The anxiety about the possibility of getting a decision wrong was common:

'She knows what's happening around her but can't communicate to us. And I think it just makes us very aware, are we doing the right thing? Are we not doing the right thing? Would she have wanted to be PEG [percutaneous endoscopic gastrostomy] fed? She may not have wanted to be PEG fed. So it's almost trying to make, to see what her wishes were, to see if she did want to. Because again if we prolong her life, if we did PEG feed her and again we don't know if that's something she would want/not want...And I think what we are worried about is if we make that wrong decision and she's aware of what's going on...And you just don't want to make the wrong decision.'

P16, senior acute care dietitian

'Oh [I feel] very uncertain. You don't know if you're doing the right thing. You hope that you are in terms of just taking everything together and what the patient would want and what the family want and what the doctors see is the best thing, and what you feel should be the best thing. Taking it all together you hope you're

doing the right thing...but just uncertainty as to am I actually doing the right thing.'

P5, junior acute care dietitian

'I think scared [that]...you're going against the patient's wishes, or that you're not considering them. But you're not considering them, because you don't know what they are.'

P11, senior acute care dietitian

Not all dietitians seemed to express anxiety at these situations. One dietitian seemed to rationalise these situations by considering how comfortable she was with the decision made. She said:

'I think that it comes down to, "Am I comfortable with this?" Not, "Do I like it, do I think it's fantastic?" but, "Am I comfortable with it?"'

P9, senior acute care dietitian

7.5.2 The repassing of tubes

Another area where participants described experiencing uncertainty about doing the right thing was the repassing of feeding tubes which had been dislodged. Some dietitians questioned whether patients might be pulling tubes out deliberately to show that they did not want to be fed, and described feeling troubled when tubes were repassed or when restraints were used to keep the tubes in place. Although the patients in these situations were unable to communicate or were confused, many dietitians were sure that the tube pulling was a deliberate act:

'Yeah sometimes when a patient's pulling a tube, is it trying to let you know they don't want a tube? And it's hard to know what their intention is and they're not just confused and pulling at it. But some patients are really determined and you do wonder with some of them. You've got no proof, but you do wonder with some of them whether they're just trying to let you know...I've got no basis for that. It's just a feeling, you know, some patients are so determined to pull tubes. And you think, "Well they've got no strength normally, they can't normally lift their arm but they still manage to pull that tube out." ...I don't know, speculation, I've got no proof or evidence if you've got a patient that can't tell you.'

P15, senior acute care dietitian

'...this lady ended up just repeatedly pulling them [nasogastric tubes] out. And I am sure she knew what she was doing, and didn't want to live. I'm sure that we did not do the right thing. I was horrified when I realised what it had led to. You know. It went from a trial to we've got to keep putting it...And I think there are people, if that's the only way of communicating, they're saying, "Don't treat me." If you've got somebody that can't communicate but has got some understanding, what else are they going to do?'

P9, senior acute care dietitian

Some dietitians coped with the uncertainty of whether it was right to feed or not by suggesting a trial of feeding. A trial of feeding is where a time frame is put on feeding, for example, two weeks. It is then reviewed to

assess if it is of benefit and whether it should be continued. If it is not of benefit, then the ANH would be withdrawn. This was particularly discussed in the context of stroke patients when there was uncertainty around the patient's recovery and rehabilitation potential. All participants who discussed trials of ANH believed that it gave patients a chance to improve because it was often difficult to predict who would improve and who would not.

'I personally feel it's a good way to do it sometimes because I don't think you can foresee the future. Erm, and there can be some very poorly [patients] who you say, "They've got no chance of recovery" and then they can surprise you...Because in that two weeks time somebody may actually pick up and have rehab potential...And somebody may just be lying there and you're just prolonging a not very nice experience for them and the family. In which case you can say, "Look we've tried it, it's not working, we'd like to consider stopping"...Because there's nothing worse than somebody who's got no prognosis, not a good prognosis being maintained just though artificial nutrition.'

P12, senior acute care dietitian

7.6 Is it fair?

Many dietitians expressed unease about the tension between prolonging life with ANH and the quality of life that patients may have. They described being unsure whether providing ANH would be of any long-term benefit to

the patient in terms of improving their underlying condition, or whether it would just keep people alive with a poor quality of life, or prolong dying:

'...when I'm covering on the elderly care or one of the other wards and then they say, "Right, tube's gone down, can we have a regimen?" And, "Okay we'll be sending them to such and such nursing home. Can we get them, you know, equipment ready and everything?" And I think, "Oh dear, this is going to be one of those who's going to be there for years?" And I just think, "I wonder what thought has really gone into it." And I don't know whether a lot of thought has gone into it, or whether it's just a quick and easy way to sort of get somebody out of hospital and into a nursing home, with no real thought of the long term...It is difficult...I don't know whether it's the right thing for that patient and that just sits a bit uncomfortable for me...[have they] really thought about what are we going to achieve with the feed?'

P10, senior acute care dietitian

'...when they [the patient] can't communicate, not alert, they're not conscious. It's just, they're just lying in a bed, basically in a drowsy state. [Pause] It just doesn't seem fair to prolong that if there's no hint that that's going to improve...Obviously, if there's any chance that they're going to improve. Like stroke patients can come in like that, and they can be up and walking after time.'

P11, senior acute care dietitian

The view that inserting PEGs into patients was a way to facilitate nursing homes to accept patients had some resonance with other dietitians who worked in acute care.

'NGs does limit the nursing home options. There's only about two I believe that will actually accept with a NG. Most will say they will have PEG but they won't have NG...they don't actually like taking on people with NGs.'

P12, senior community dietitian

'She'd come in from a nursing home and if she wasn't going to get this PEG the nursing home weren't happy about having her back. We've had this problem in the Midlands where nursing homes say they only take or only have PEGs when patients go to them rather than NG feeds.'

P13, senior acute care dietitian

While many were unsure about the benefits of ANH in certain situations and were uneasy about this, one dietitian believed that this might happen because relatives encouraged doctors to feed; that was previously described in section 6.6 'Silenced', when families seemed to have more influence on decisions than dietitians did. This dietitian believed that patients might be treated, even though ANH may not be of benefit, because doctors want to treat and are not very good at letting patients die. She was troubled by this. While she empathised with the doctors' view, she was conflicted, as it may result in patients surviving with a poor quality of life:

'...the doctors, they want to treat. They get a diagnosis and they treat it. And there's always that attempt to make somebody better. And I know one nurse said, "You can't make everyone better." She said, "You dietitians, you're like doctors - you want to make everyone better. And at what point do you stop?"...And yeah, I probably do think like that, that desperate attempt to make someone better. But then I'm battled by working with people that have been severely disabled, and seeing the long-term bit of it as well.'

P2, junior acute care dietitian

So some dietitians appeared troubled by feeding some patients, and they wondered whether it was the right thing to do. One dietitian described her struggle of trying not to let her personal views influence decisions. She described the difficulties associated with this in her interview:

'I try [to] introduce them [the patient] to someone, somebody with a PEG. But again you can pick those patients...that's had a brilliant experience and thinks the PEG is the best thing since sliced bread. So again you are throwing in a bit of bias...I am [uncomfortable about that] 'cos it may not be the same for them and you're painting them this picture that it's going to be wonderful...I think for progressive neurological conditions, they are palliative so it's less clear what the benefit is...when it's somebody who's got a deteriorating intake for whatever reason...it's less clear about whether it's going to benefit them nutritionally...When patients ask, "What benefits will I get from this?", I have to try and say, "Well you

could”, but I’m beginning to doubt if it’s a good thing to do...It’s very difficult. Erm, ‘cos I’m not sure if it’s my own personal feelings that are coming through or I’m taking from what I know and giving them that [clinical] experience, I’m not sure...I love working with motor neurone patients, it’s very rewarding, but I’m not sure I want to talk about PEGs any more [laugh] to be honest...And sometimes I feel quite relieved when they say I don’t want a tube.’

P4, senior community dietitian

The phenomenon of ‘Is it fair?’ is interesting, as it might be expected that dietitians would be promoters of ANH regardless of the situation, as it is their job to provide adequate nutrition. However, many of these dietitians were not just thinking about ANH as fuel and blindly providing nutrition, they were thinking about the bigger picture and their patients’ quality of life and longer term outcomes as well. One participant described this when she said:

‘And if obviously feeding this patient is what is best for them I’d be saying, yeah put a tube down and start feeding them. But if it’s not what’s best then we can’t do that. Because sometimes nutrition can keep someone alive but again it’s back to are they going to have any quality of life?...And that’s not what’s best for him.’

P14, junior acute care dietitian

The quality of life issues considered related to having little or no function or communication, but they also considered the effect on family life which

may occur when someone receives long-term ANH for example, the possibility of no longer being able to live at home. This was troubling for a participant who was very aware that patients wanted to go home and not into a nursing home, as described in section 7.4 in this chapter on 'It's my fault'.

7.7 Moral distress

Moral distress is the emotional response that is experienced as a result of doing something believed to be wrong (Jameton, 2013). To feel moral distress, there must be certainty in the belief of what is right and what is wrong to do in a given situation. A few dietitians seemed to describe moral distress, mostly related to feeding at end-of-life or long-term feeding in poor quality of life.

'...what I want to do and what I should do and what I'm being told to do are very different things...I think with some patients part of me says, because normally I come and see them there's a tube in somewhere and part of me just wants to say, "Well why did you bother putting a tube in this person?" You know, "Why?" And part of me wants to say, "Oh no, we're not going to feed them." But what I should do and what I've been told to do is do a NG regimen. And of course I just do it. Even though I suppose what my belief would be would be to let the patient go to a better place.'

P14, junior acute care dietitian

'I've got lots and lots of patients that come out of hospital with a PEG, it's the only thing keeping them alive and they stay like that

for a couple of years. You know, they're not conscious, they're fed and well, they are conscious but they've got, there's no responses, err, there's no communication...Just lying there, fed and having their medication and that's it. And the poor family have to keep coming to visit and it's just horrible...I think they look to me as if I've advocated it, as if I was the part of the decision-making...I do think that eyes are boring in the back of my head sometimes [laugh]...and the nurses will say to me, "Oh that's no life is it".'

P4, senior community dietitian

While P14 expressed how sad she felt about the situation, she felt she needed to be involved to ensure the that feeding regimen was safe and appropriate for the patient.

Potentially unsafe feeding caused moral distress for one participant when she was asked to feed a patient without recent blood results:

'...feeding on no blood results, where you just feel totally out of your depth [pause] and unsafe but you're being made to do something that you think is unsafe.'

P11, senior acute care dietitian

While most of the moral distress displayed was related to feeding at end-of-life or feeding in poor quality of life, one participant discussed her moral distress at having to treat a patient who had a PEG when the dietitian did not believe it to be indicated:

'And my instructions were start feeding. It was horrible, to the point to where I didn't even introduce myself to her. Because I was just so uncomfortable with what I was doing...I thought it was horrific. Absolutely horrific.'

P2, junior acute care dietitian

This dietitian described strong emotional experiences, partly because she did not believe that feeding was indicated, partly because she was not heard during the decision-making process, but also because she believed that providing ANH was detrimental to the patient's overall care as the patient was not getting the psychiatric input she needed.

It appears that some dietitians were being put into positions where they were treating patients even though they did not agree with it. This might be due to the dietitians feeling powerless; for example, when they did not feel they had the power or authority to speak up or change a situation. This might be related to undertaking more of a technician role or due to family pressures to provide ANH as described in previous chapters (sections 5.5 and 6.6). Moral distress is important because it can lead to distancing from patients (Varcoe *et al.*, 2012b), desensitisation, and disengagement with patients (Varcoe *et al.*, 2012a). Moral distress has been reported in doctors (Austin *et al.*, 2009; Rushton *et al.*, 2013a; Rushton *et al.*, 2013b), nurses (Austin *et al.*, 2005; McCarthy and Deady, 2008; Pauly *et al.*, 2009), and other healthcare professionals working in palliative care (Brazil *et al.*, 2010), even in NHS managers (Mitton *et al.*, 2011), but not within dietetics

before.

Not all interviews suggested experience of moral distress; this might be because some participants had not been placed in a position of being forced to do things that they believed were wrong. However, as described in the section 'Is it fair?', many appeared to feel uneasy with ANH being provided for some patients, and a feeling of anger (as previously described in this chapter) has been associated with experiencing moral distress in some situations (McCarthy and Deady, 2008).

7.8 Don't show it

During my engagement with the data, it became clear that many of my participants respond to their emotions in a range of ways. Many dietitians appeared to feel that they needed to hide their true emotions. The participants' accounts seemed to reveal that they hid emotions such as outrage, anger, frustration, and sadness.

Many dietitians talked about finding themselves in situations where they felt unsure if the decision was the best or appropriate for their patient, and described feeling uneasy about the provision of ANH because of a decision or the actions of others. The actions of others had knock-on effects for them. One participant summed up what many others had expressed when she stated:

'We turn up and deal with the consequences of it.'

P14, junior acute care dietitian

The account of a senior community dietitian illustrated the need to hide her true feelings in front of a patient's relatives, when she reviewed a patient at home on a percutaneous endoscopic gastrostomy (PEG) feed. The patient's relatives said that the patient would not have consented to having a PEG. The dietitian described how she felt outraged that the patient may have had a procedure that he may not have been able to consent to due to a possible lack of capacity. Her account illustrates the anger and frustration she experienced when she could not express her true feelings:

'It's terrible. I think it's disgusting [pause] that well, the legal implications of that are huge. Really, that is assault, isn't it. That you do a procedure on someone and they haven't consented...And they were you know, 99% sure it wouldn't have been what he wanted...It's difficult, because...you can't say, "Oh isn't the NHS rubbish." [Laugh] And you can't say, "Aren't the doctors rubbish." Or, "Wasn't that decision rubbish," you have to say, you have to be quite tactful and say, "I understand that you're unhappy about it." And I did say, "If you want to make a complaint this is the procedure to make a complaint." But often people don't complain because they feel it's going to be difficult...So [sigh] I did sort of say, "I know" a lot [laugh], "I know", "I know!" Erm, but couldn't really say a lot more than that...[And you feel] horrible. You feel like you're letting yourself down and your principles down really. But we are told you know, not to bad mouth the NHS because it doesn't help. And it doesn't I suppose.'

This participant expressed strong and powerful emotions in her interview, but was not able to express them to the patient's relatives. This suggests that the dietitian was undertaking emotional labour; in this case it was the suppression of feelings, as dictated by the organisational display rules which stated she should not 'bad mouth the NHS'. She seemed to conform to this organisational display rule so as not to inflame an already difficult situation with angry relatives. While this dietitian's account suggests that she was loyal to the NHS, she showed a sense of feeling outraged by the situation and was critical of the doctors who obtained 'consent' from the patient who may not have had capacity to consent or may not have wanted a PEG. This dietitian responded to her emotions of outrage and anger by suppressing them, but that led to a new emotion, of her feeling horrible because she had not matched up to her own high principles.

Another dietitian's account suggested an experience of frustration and anger when she was left to deal with an anxious patient following a doctor questioning the patient about the feeding regimen she was receiving. The dietitian described how she had worked hard to try not to undermine her senior medical colleague, but given the situation she had no choice to undermine him to a degree, which left her feeling awkward and embarrassed. The dietitian had already spent a lot of time with the patient who was anxious about her care, so the dietitian said that the priority for

her was to stay calm in front of the patient and not to show her own emotions, to try to reduce the patient's upset:

'...for a doctor to say, "Oh no, you should be on a feed, bolusing Fortisips it's not good enough."...she [the patient] caught me on the ward the next day, was very upset, very worried, saying, "Am I doing the right thing now? Are you telling me to do the right thing?" It was just [pause] it was a bit, I don't know, frustrating...Because I spent so much time with her because she's such an anxious lady...For a consultant to go in and say that to her...And they always choose to take the consultant's word over a dietitian's word. So trying to overrule that comment was just, took so much time...But it was quite hard not to sort of undermine the consultant because he is a colleague so it's quite difficult to get around that situation...it's a bit embarrassing...[a] bit awkward...[because] they [the doctors] sort of put me in it...it's very difficult, I just had to try. Even though I was really angry, I had to just try and keep my cool and try and calm her down.'

P7, junior acute care dietitian

This dietitian's hiding of emotions suggests that she undertook emotional labour to reassure the patient that she was having the right treatment. The British Dietetic Association's code of conduct states that 'you should not criticise any colleague in public' (The British Dietetic Association, 2008a:15), suggesting that the dietitian was also trying to conform to an organisational display rule by trying not to undermine her senior colleague.

The experience of not wishing to appear disloyal to medical colleagues leading to emotional labour has been previously reported within British palliative care nurses (Li, 2005), but not within dietetics.

Participants also described suppressing emotions of frustration, due to only having a limited amount of time to spend with patients. This was illuminated by a dietitian who was mindful that patients want to communicate at their own pace. This seemed to cause the dietitian frustration from a time management point of view, although she was careful not to show this frustration by undertaking emotional labour and appeared to surface act:

'The other thing I'm quite aware of is that those type of consultations [where there are communication problems] take longer. They do take longer and you have to really be aware that you don't show to them that you're maybe slightly frustrated because you know what the next word is going to be by the phrase, but she quite definitely wants to tap it in.'

P8, senior community dietitian

Surface acting during emotional labour has been described as the ability to deceive others about what is being felt, without deceiving oneself (Theodosius, 2008; Hochschild, 2012), or as faking it (Ashforth and Humphrey, 1993; Pisaniello *et al.*, 2012). Surface acting involves consciously changing external expressions regardless of how one feels inside (Smith, 2012). Although the expressions have been changed, the

inner emotions remain and so the individual will continue to feel the unresolved, often negative emotion (Hülshager and Schewe, 2011). Therefore, it has been suggested that surface acting results in an inauthentic view of self (Ashforth and Humphrey, 1993; Theodosius, 2008; Restrepo and Pilgrim, 2011).

This dietitian appears to be surface acting, as she seems to be irritated by the amount of time it was taking for the patient to communicate with her, but she did not show it. It might be argued that she was putting on an act, so giving an inauthentic view of herself. Although for understandable reasons, in effect she was not being truthful. Honesty and truth telling are part of the dietitians' code of conduct (Health and Care Professions Council, 2016) so there can be a tension for some participants. They are undertaking this surface acting with good motivations and intentions, but it might go against their professional code of conduct or their own moral values. A feeling of a lack of authenticity was evident in P4's account described earlier, when she stated, '*You feel like you're letting yourself down and your principles down really.*' A lack of authenticity has been described in other healthcare professionals (Ashforth and Humphrey, 1993; Theodosius, 2008), but not within dietetics before now.

'Don't show it' was also illustrated by a junior dietitian when she talked about an elderly patient who needed ANH. She described how she felt sad for the patient, who was very frail and could no longer go home as he was receiving ANH which his family felt they could not cope with. She also felt

vulnerable in her clinical practice, as she was unsure of the best course of action to take. She seemed to think it was unprofessional to share these emotions, so she did not show them:

'But sometimes it does make you feel down and sad because you're just like, "Am I doing the right thing?"...and you can't say how you're really feeling. And you're just like, "I should be able to say how I'm feeling but it's not always professional"...I get too emotionally attached sometimes. And then that makes me think, "Oh should I really be doing this?"...But sometimes when you're dealing with sensitive issues it does make you question your practice a little bit...And [I] feel vulnerable a little bit. Because you don't get lessons at uni about ethics really do you? You don't get given classes on how to deal with ethical situations or how you would feel.'

P1, junior acute care dietitian

This participant appeared to feel ill-prepared for the situation and her emotional response to it. She seemed to believe that showing her emotions was unprofessional. While empathy is important to show (Abbott Moore, 2010), it has been suggested that showing uncontrolled negative emotions is unlikely to be beneficial to patient care (The Scottish Government, 2012). This will be further explored in Chapter 8.

A further situation where one participant did not show their emotions was related to her religion and faith. A junior dietitian recounted hiding her

strong emotional reaction to a clinical situation during her interview. She described a patient that she cared for, who (in her view) had a poor quality of life, was in pain, and was receiving ANH. The dietitian's faith appeared to influence her feelings towards feeding this patient, as she felt that he was suffering, and if he died he would go to 'a better place' and it would alleviate his suffering. She felt that she could not show her feelings about these types of situations because her emotions were rooted in her faith. She thought that if her feelings were expressed it would lead to complaints by patients and disciplinary action for her:

'...if we didn't feed this patient, I mean obviously the patient would die if we didn't feed them, but part of me thinks, "For the quality of life they have is it really worth feeding them and keeping them alive this long?" And they don't even know where they are themselves. And I just think that's quite sad really. So I get quite conflicted in that sort of area...part of me says..."Well why did you bother putting a tube in this person? Why?" And part of me wants to say, "Oh no, we're not going to feed them". But what...I've been told to do is do a NG [nasogastric] regimen, and of course I just do it. Even though I suppose what my belief would be to let the patient go to a better place...maybe it's to do with some of the beliefs we discussed at the beginning with me being a Christian and thinking people will go to a better place. Maybe thinking about people's pain...as well...but obviously that's something you can't express with the patient...we live in a world...where you can say one thing wrong and the next

thing you're in the newspapers...or brought up in front of the head of department...'

P14, junior acute care dietitian

This dietitian's emotional response to suffering seemed to be rooted in her faith. However, if she shared her beliefs, and therefore her emotions, she was fearful that it might lead to complaints about her and the effect it might have on her career. Hiding of faith has been noted in other professional groups where it is felt that there is a possible conflict between faith and a professional role (Geller *et al.*, 2009). This hiding of emotions related to faith is of interest, as faith has been shown to influence decision-making related to ANH (del Río *et al.*, 2012). By not disclosing one's faith or beliefs any influences they may have on decision-making then become hidden, which may not be best for decision-making within a team.

7.9 Keeping a distance

When faced with emotive and difficult situations, avoiding a situation or keeping a physical or emotional distance from the key players can be a way of protecting oneself from the emotional fallout (Varcoe *et al.*, 2012b). This appeared to be the response a few dietitians had to their emotional experiences. For these dietitians it was related to situations where they did not agree with or were uneasy about the decision to feed.

The dietitians' accounts suggested that some distanced themselves from the family when they believed that it was inappropriate to provide ANH and

distanced themselves from difficult conversations about withdrawal of ANH. For some dietitians there was a tension between being a provider of nutrition and feeling that some patients should not be fed, which led to feelings of conflict. There seemed to be an appreciation that in some situations just fuelling a body was not appropriate; however, in the account below, the dietitian was fearful that others would not have the same view, so it was just easier to avoid the situation. This dietitian alluded to people believing that feeding patients makes them better. She also appeared to be concerned about professional repercussions for her as a dietitian: that a dietitian could suggest not providing ANH:

'I think if you know the family's got a real issue you kind of put off going to talk to them. You think, "Oh no, what am I going to say to them?" I particularly avoid, I've got to say, I avoid situations where I don't think it's appropriate to feed.'

P11, senior acute care dietitian

'I suppose if I was the one to initiate it [discussion about if ANH should be withdrawn] I would be scared that they thought, "Wait a minute, are you trying to kill this patient?"...And imagine if the family heard, "Oh by the way did you know the dietitian suggested stopping feeding your family member?" You wouldn't want that to get twisted around the wrong way. So I guess there's a fear of that...I think in general the health professions like doctors, health professionals, everybody, nurses, we're all quite scared of death and talking about it and ending treatment or thinking as I say, about

appropriate treatments...it's so instilled what we're there to do. Feed people up and make them better...'

P11, senior acute care dietitian

'It's that waiting, isn't it, and that feeling of, "Oh no, I'm keeping this person alive and are they going to get any better?" And having to go in and see their family every day when I review them. And wonder what they think. I'm too scared to ask them what they actually think...About how things are going really and about the feeding, whether they start to think was this a good idea or not...I think I always worry that they think it's going to make a big difference, and I don't actually want to say to them, "I don't know" and for them to say, "Well what if it doesn't make a difference?" 'cos all those fears that I already have.'

P2, junior acute care dietitian

This dietitian was uncomfortable about feeding patients who she believed had a poor quality of life. In this account she talked of being fearful that patients were just being kept alive and would not improve clinically. In the last chapter this dietitian expressed that fear as being '*mortified*' and that '*it was just horrendous*'. Here she appears to distance herself from the relative because she did not want to answer difficult questions about whether the patient would get better or not, because she did not know and she was troubled by people being kept alive by ANH when they have little cognitive or physical function.

The same dietitian also spoke about keeping a distance from a patient (who was sectioned under the Mental Health Act) who, in her view, was being PEG fed inappropriately. The dietitian believed that the team should have persevered with oral supplements rather than making the decision to insert a PEG. The dietitian knew she would have to treat the patient long term and could see that the patient was distressed at having the PEG, so for her to have a long-term therapeutic relationship with the patient, she decided that she needed to distance herself from the situation:

'And my instructions were start feeding. It was horrible, to the point to where I didn't even introduce myself to her. Because I [was] just so uncomfortable with what I was doing and a bit of me also felt that I'm going to get this person eating so that she doesn't have to keep this [PEG]...If she knew that I was doing that, my rapport would have been trashed forever and I would never have achieved that, so I stayed back and that made me feel even worse. But I mean, I did do it for her benefit, but I was actually quite relieved that was the choice that I'd made.'

P2, junior acute care dietitian

The physical and emotional distancing this dietitian decided to undertake seemed to be in response to the moral distress she felt. In distancing herself from the patient she experienced another emotion, as she felt uncomfortable with what she did.

The phenomenon of distancing also became apparent in the interview of a senior acute care dietitian. She discussed providing ANH to a palliative care patient who had a complex social situation. She was aware that she was emotionally distancing herself from the patient. She said:

'...it's not meant to seem cold [not wanting to get emotionally involved], but, you know, we've got to keep clinical, you know, we're there to do a job. I'm there to be a dietitian, I'm not there to be a counsellor or I'm not there to solve the situation...I'm getting quite practised, you know, going in and being the dietitian without having to get emotionally involved.'

P13, senior acute care dietitian

This dietitian concentrated on her clinical role of ensuring that ANH was provided safely and effectively rather than engaging with a very difficult emotive situation. She was saddened by the hopelessness of the situation, and responded to this by concentrating on the technical aspects of her job rather than the emotional aspects.

Distancing from difficult emotional situations in response to emotions has been noted in other professions, such as nursing (Miller *et al.*, 2008; Wassink and Chapman, 2010; Varcoe *et al.*, 2012b) and medicine (British Medical Association Medical Ethics Committee, 2007; Liben *et al.*, 2008; Moreno-Jiménez *et al.*, 2008; Lee *et al.*, 2010; Burks and Kobus, 2012) but not within dietetic practice before now.

7.10 Becoming desensitised

It has been suggested that working in an emotive environment can lead to some people becoming hardened to the emotions of a situation; they become desensitised to it (Kuczewski *et al.*, 2014). 'Becoming desensitised' was apparent in some participants' accounts. Participants described becoming a little blasé at people's emotions and compared it to the detachment doctors might experience. One participant suggested that some dietitians may have to become a little desensitised, to put up a barrier to protect themselves from harm. However, the same dietitian was troubled by this. While she appreciated that it was likely to happen due to the nature of the job and the environment, she believed that becoming desensitised would result in caring less for patients and this concerned her:

'I think when family use that word [starve], it's obviously a lot of emotion in there. They see their perspective, they don't see anything that's going on in the background. And it is quite harsh, it sounds harsh. I suppose you kind of [sigh] yeah, not numbed to people's emotions. Suppose you are a bit because you see, you become a little bit blasé, when you see these sort of situations day in day out. And it's good to be reminded how it comes across to the family.'

P11, senior acute care dietitian

'You have to put feelings aside sometimes and see the black and white of it [making decisions about to withdraw ANH]... You have to see how the doctor thinks in a way...It's not like I've become

desensitised, I have a little bit. But you kind of switch off from the emotions of it...they [doctors] see life and death every day really. I think they become not blasé, but I suppose you have to form some kind of barrier to yourself...'

P1, junior acute care dietitian

'I think the hospital environment desensitises you a little bit as well. Like it's not as raw as when you first go in it. But I don't want to lose my caring, empathy at the same time. You get used to it...I don't want to get to the stage where I'm desensitised to it either. Like it's so blasé...he'll probably die. Because that wouldn't be part of who I am. I like being caring. I like getting involved with my patients. It means something to me. Otherwise, you wouldn't...be caring.'

P1, junior acute care dietitian

These accounts suggest that while becoming desensitised can create a barrier which may help to protect oneself from the emotions of a situation, there was concern that it may have professional implications as it may leave the dietitian unable to adequately care for their patients. This resulted in a new emotional cost for them. 'Becoming desensitised' has not been noted within dietetics before now.

7.11 Speaking out

The response some dietitians had to their emotional experiences was to speak out. For many of my participants, when they experienced situations where patients were not being respected, they felt that they needed to say

something in response to the injustice. One senior acute care dietitian's account of working on general wards included her irritation that a patient's autonomy was not being respected. She responded by speaking out about the patient's care:

'And I've gone along and said, "Hang on a minute, what's going on with this?" And I'm challenging things...because I will question them [doctors] at times, whether things are appropriate. I mean we had a patient, it must have been at the beginning of this year who, very advanced dementia again, came in with a stroke. And I think it had been previously documented about how he didn't want a tube. And they kept on trying with a tube. And the doctors kept on insisting to try with a tube. And I was like, "Hang on a minute. Look, stop. Let's discuss this before you keep putting a tube down this poor man"...so I would challenge things, but not everyone will...a lot does come with experience...[and] confidence...and seeing how it can be handled differently.'

P15, senior acute care dietitian

This participant appeared to believe that she was able to act in this way because she had the experience and confidence to speak out, something that she thought her junior colleagues lacked. The irritation she felt in the situation prompted her to act, which could be interpreted as moral agency. Moral agency is being able to think and act in a given situation and to take responsibility for that action (Carpenter, 2010; Lützén *et al.*, 2010). For the action to be moral, it needs to be grounded in professional or personal

moral or ethical standards. 'Agency' suggests that the person acting has the ability to influence change (Edwards *et al.*, 2011). This dietitian's irritation may have been rooted in her professional standards of respecting autonomy, and her experience and confidence suggested that she believed she could influence the doctors: both factors suggesting her moral agency.

Emotions of concern and unease about a patient appeared to result in one community dietitian speaking out. She was concerned because it was unclear if the patient had the capacity to make a decision. She was uneasy about whether the patient wanted a PEG inserted or whether it was in the patient's best interests to have one. Rather than thinking it was someone else's problem, she spoke out and took on the responsibility to act:

'I think with capacity, people shift it along, "Oh well I can't make that decision, somebody else will have to do it", and, "Somebody else will have to do it"...I've written to her neurologist to express my concerns about her capacity for the decision of PEG...I've got concerns and I would not be doing my job if I didn't express those concerns...we really need to make a decision on her capacity first...As far as decision by decision, I do think that if you've got the most information about that decision then it should be you [to assess a patient's capacity]. So I kind of think it should be me that makes that decision about this one, but I don't want to [pause], it's difficult, isn't it. I don't want to put myself forward saying well I'm the

expert...in assessing her capacity, because I don't think I am, but I am for this decision. And I need to make that clear.'

P4, senior community dietitian

This dietitian spoke out as she was concerned about her patient. She appeared to have acted as a moral agent, as she spoke out about her concerns for consent and the best interests of her patient. She also seemed to accept the responsibility of speaking out, but was troubled by putting herself forward as the expert. Her turmoil may have been associated with her feeling that she had the expertise to make *this* decision for *this* patient, but not that she had the expertise to make other decisions on other patients' capacity.

The difficulty of speaking out was expressed by another participant. She described how her own morals supported her to speak out when she felt that care had not gone as it should:

'I suppose if you speak out a bit...that it really hasn't been for the good...it is your own personal perhaps morality I think and experience as well. It's easy to ignore them, isn't it. Easier sometimes, yeah.'

P6, senior community dietitian

One dietitian (P15) suggested that her junior colleagues did not have the experience or confidence to speak out. However, within my data it is not as clear-cut as she suggests, as not all senior dietitians acted as moral

agents. While some dietitians' accounts did acknowledge the difficulty of situations, they did not speak out to express their concerns for their patients:

'But he didn't want NG feeding at any cost...On discussion with the Macmillan OT, the same OT was going in and the district nurses, they felt that it [refusing the NG] was his way of indicating well actually I don't want to carry on. You know, I don't want to fight anymore. Increasingly, he'd become more tired as he lost weight, didn't want to carry on any more and that was his way of asserting that. But [he] would never say that in a way, wouldn't be as open about it to his daughter to admit well actually, I've fought long enough...But at the time you do get engrossed in the situation and obviously the relatives as well. They were very keen to have the PEG placed...And I was then starting to think, well...somebody in this situation, whether that was appropriate. Though she was very much, the granddaughter, she wanted everything done that possibly could be done. And so it is very difficult when you're caught up in that scenario. It is difficult.'

P8, senior community dietitian

'I suppose I didn't have the guts to say that [consider withdrawing ANH] to be honest...'

P11, senior acute care dietitian

So while some dietitians spoke out and acted as moral agents, not all did.

This is the first report of dietitians acting as moral agents.

7.12 Needing support

Many dietitians described the support they needed as a result of the emotive situations they experienced. Dietitians received support from a number of avenues. This may have been formal clinical supervision sessions or informal support from dietetic colleagues or the wider multi-disciplinary team. Support from non-professional friends or family was not always considered helpful because of the nature of the professional role. Several dietitians expressed that talking about emotive situations with dietetic colleagues helped them cope:

'Just to make it easier on your head so that you're not going home thinking about it...But on the whole, I go for guidance. I go, "This is how I'm feeling, is this right?" or this is what I do with my supervisor anyway. I'm like, "Is it right?" And sometimes they go, "Yeah that's fine." And she knows I get emotionally attached anyway, so she's quite grounding. I like having grounding people around me. And I suppose in a way I still need people around that will do that. Because you can't go home and talk about it, they don't know really what we do. And it helps if you talk to another dietitian. And especially if they're a bit experienced.'

P1, junior acute care dietitian

'And I don't stop thinking about it. So I think I'm churning it over all the time...And I think that's where our team is good. Because everyone's going to have a different idea of what they think is ethical and what isn't. And I think that's important as well. People

have different boundaries don't they. And different things bother them. And I think discussion is a good thing.'

P2, junior acute care dietitian.

For these dietitians, talking to a colleague was helpful, providing an opportunity for support and discussion of moral issues. These quotes illustrate how senior colleagues as well as other team members are important sources of emotional support. The churning over of emotions was troubling for the second dietitian, participant P2. She said, *'It can be disturbing...'* so discussion was helpful for her.

It was not only junior dietitians that identified the need for support. Gaining support from colleagues when dealing with emotive cases was expressed by senior dietitians also, either through informal approaches or from dietetic colleagues and other multi-disciplinary team members working in similar clinical areas to reduce the feeling of isolation:

'I think with these sort of emotive cases it's almost a case of just having someone you can say to, "Look, can I have a hug?" [Laugh] And just getting it out. But I think my main support would be from within the team, because we'll all be going through it together.'

P15, senior acute care dietitian

'We used to have a psychologist as well which was brilliant but unfortunately she left. So, umm, we could talk about our emotions as well and support for us because it's really quite a difficult area to work in. There is no happy ending for any of the patients so, umm,

you do need a lot of support from your colleagues...I think [pause] it's a quite a difficult area to work in. Usually, there's one of you for a trust or an area and that can be quite isolating, quite scary. So you have to build up networks, you have to get support for yourself, which you need to be quite a confident person to do. And I think sometimes you need that support.'

P4, senior community dietitian

It is important to note that not all participants had access to supervision due to time constraints.

'We did do some clinical supervision some years ago but we've so many changes of staff it was really difficult to follow it through and people to commit the time.'

P9, senior acute care dietitian

Within dietetics the need for supervision has been recognised for some time (Kirk *et al.*, 2000) and it is considered integral to ensuring the delivery of a quality service (The British Dietetic Association, 2011). There are also training implications for supervision, as training to develop the appropriate skills are often needed (MacLellan and Lordly, 2008; Walker and Grosjean, 2010).

7.13 Conclusion

This data suggests that dietitians have a range of emotional experiences in their clinical practice related to decision-making with ANH and respond

to them in a number of ways. The emotional experiences seem to be influenced by how comfortable the dietitian felt with the decision made. Many felt proud of the job that they undertook and felt they made a positive difference to patient care. However, a feeling of anger was common when patients were treated unfairly, or if their expert view was not recognised. A feeling of guilt was often related to normal discharge plans. Adequate information giving to the patients or relatives about long-term feeding may have mitigated some of these difficulties. Dietitians would be ideally placed to provide this information if they were involved in the decision, and a lack of information giving has been reported by UK patients and relatives before (Liley and Manthorpe, 2003; Brotherton and Carter, 2007; Brotherton *et al.*, 2007a; Brotherton *et al.*, 2007b; Vesey *et al.*, 2008; Brotherton and Abbott, 2009). Many dietitians felt uncomfortable when patients were being kept alive with what they believed to be a poor quality of life, and they were unsure about the benefits of ANH in some situations. For my participants, being a good dietitian seemed to be more than just being a technician and providing the correct nutrition; it was about trying to understand the patient's needs as a whole, which is likely to have an emotional cost for them as healthcare professionals.

While some participants did have extended roles, such as the drawing up of advance directives with patients, which can generate strong emotional experiences as they can involve talking about and planning for a patient's death, the situations recounted in this chapter were all as a result of undertaking their normal role. These included situations where the dietitian

was the primary decision maker, as well as situations where others made the decision. Having an emotional response to these situations suggests that these dietitians not only cared about their patients but that they also had difficulties when they were not heard and they believed that some decisions made could adversely affect patient care.

The lived experience of emotional clinical situations related to ANH led many of my participants to respond to their emotions in a range of ways. Some did not reveal their true inner feelings; they hid their emotions. The motivation for this emotional labour was mixed, and included wanting to show that patients were cared for, but also for self-preservation. Some responded by keeping a distance to protect themselves from the emotional fallout. Others started to become desensitised to their emotions. Some were aware of becoming desensitised and this troubled them, but it enabled them to put up a barrier to protect themselves. Some responded by acting as moral agents to try to implement a change, and some participants did not feel adequately prepared for the situations they encountered. The response to emotional experiences seemed to result in some new emotional experiences for some, which could be troubling.

Emotional labour seemed to be undertaken by the dietitians participating in this study, which has not been revealed within dietetics before. The current definitions of emotional labour do not quite capture the range of emotional labour that the dietitians undertook: the definition may need to be expanded to encompass the lived experience of dietitians. This will be

explored in more detail in the next chapter. It is also interesting that undertaking emotional labour seemed to have an emotional cost for some. This included a feeling of lack of professional and personal integrity. Some felt that by hiding their emotions they were not being truthful to patients. In distancing from patients, for some there was an emotional cost insofar as undertaking an action they did not feel comfortable with, as they believed that it may have had a negative effect on patient care.

The three findings chapters have illuminated dietitians' experiences of involvement in decision-making regarding the provision of ANH. The range of roles has been outlined, the desire to want to be heard during decision-making has been revealed, the range of emotions experienced has been illuminated, and how dietitians responded to these has been explored. This thesis will now go on to discuss these findings.

Chapter 8: Discussion

Dietitians are health professionals who have an important role in the provision of artificial nutrition and hydration (ANH). They have the skills and knowledge to identify patients at risk of malnutrition, and those who are malnourished. They are involved in the prevention and treatment of malnutrition by assessing and monitoring patients who receive ANH. As part of the multi-disciplinary team, dietitians should be involved in decision-making about ANH (Andrews, 2004; Armer and White, 2014). Dietitians are regulated by the Health and Care Professions Council's standards and code of conduct (Health and Care Professions Council, 2013; Health and Care Professions Council, 2016), and if they are members of the British Dietetic Association, they have to adhere to the British Dietetic Association code of conduct (The British Dietetic Association, 2008a).

This study has explored the lived experiences of involvement in decisions about ANH among a sample of dietitians from the Midlands, UK. In this chapter I will reflect on the findings of my research by situating them in relation to the literature. As interpretive phenomenology aims to understand people's experiences (Harris *et al.*, 2009), I will then try to make sense of the findings by using the conceptual framework of professionalism to understand these experiences and explore challenges faced by the profession. The conceptual framework of professionalism was chosen, as many aspects in the dietitians' accounts were related to their professional identity or professionalism, for example, the roles they

undertook and their experiences of trying to be an expert involved in decisions. This raises professional issues of autonomy, discretionary judgement, and team working. How much autonomy do dietitians have over this area of their practice and what does that mean for them as a profession? The emotions my participants experienced and how they responded to these are also important aspects of professional practice. Therefore, the conceptual framework of 'professionalism' will help me to understand their experiences, conceptualise these findings into new knowledge about dietitians and professionalism, and to consider the challenges to professionalism that dietitians may face.

Professionalism will be discussed in more detail in section 8.3, but to inform the discussion of the findings it is useful to briefly explore the term 'professional identity', and my use of the term. Within medicine, professional identity has been defined as 'the perception of oneself as a professional' (Weaver *et al.*, 2011:1221), and when an individual identifies themselves as part of a profession by developing and obtaining relevant 'knowledge, skills, attitudes, values, and behaviours' (Wong and Trollope-Kumar, 2014:490). Similar definitions have been used within nursing. Ten Hoeve *et al.* (2014) suggest that professional identity is defined as 'the values and beliefs held by nurses that guide her/his thinking, actions and interactions with patient' (ten Hoeve *et al.*, 2014:303). For Hercelinskyj *et al.* (2014), professional identity is 'the integration of the personal values of the nurse, understanding and motivations regarding nursing, and the internalization [sic] of the knowledge, skills, and attitudes' (Hercelinskyj *et*

al., 2014:25). Therefore, professional identity is about the individual's view of their own professional values, knowledge, and behaviours; it is the way the individual demonstrates that they are part of the profession. Therefore, when I use the term 'professional identity', it is to show how my participants embody what they seem to think being a professional dietitian is.

However, I will start by briefly revising the aim and objectives of the research and the methodology and methods adopted.

8.1 The guiding research question

The question guiding this research was 'What are dietitians' experiences of being involved in decisions relating to ANH?' To answer the research question, the objectives of this research were:

- To explore dietitians' perceptions of their role in decision-making about ANH.
- To explore how different contexts influence dietitians' experiences of decision-making about ANH.

The data was collected via two separate one-to-one interviews with 16 dietitians from a range of clinical settings and with a range of years of experience. The focus of the second interview was a reflective account of a personally experienced clinical event related to decision-making about ANH. The data was analysed using an interpretive phenomenology framework.

8.2 My findings and the related literature

This section will review the themes which emerged from the data and relate my findings to the wider literature. Links will be made between the four themes described in the previous findings chapters to illuminate the lived experience of dietitians' involvement in decision-making related to ANH.

8.2.1 'So much more than just deciding on a feed'

'Expert', 'educator' and 'advocate'

The theme 'so much more than just deciding on a feed' illuminated the varied roles that my participants described as part of their everyday lived experience of decision-making related to providing ANH. The data illustrated that the roles of 'expert', 'educator', 'advocate', and 'technician' were core to the everyday working lives of my participants. The dietitians saw themselves as experts, regardless of grade or level of experience, and used their expert skills within the roles of expert, educator, and advocate. Their identity seemed to be one of a skilled professional expert. When participants did not agree with the decision made, it led to problems for them. Therefore, the lived experience of dietitians' experiences related to ANH was influenced by which of these roles they undertook.

As the dietitians' professional identity seemed to be in part related to their expertise, when they were not recognised as experts it created professional challenges for them, as professional identity is related to professionalism (Wong and Trollope-Kumar, 2014). Other aspects of

professional identity seemed to be around patient-centred holistic care: in their advocacy role, dietitians acted more broadly than just considering ANH and described a holistic view to patient care. Their advocacy role also included advocating for nutrition and dietetic services to raise the profile of dietitians, and raise awareness of malnutrition and the need for nutrition support. These aspects of patient-centredness, advocating for patients and excellence, have been identified as key aspects of nurses' and midwives' professionalism in a Delphi study by Mogan *et al.* (2014).

There is very little evidence of UK dietitians taking on the 'expert' role, and what there is implies the adoption of expert roles rather than explicitly stated expert roles being undertaken. Stanley and Borthwick's (2013) study implied that their cohort of six British community dietitians working within home enteral feeding services took on an expert role, as they extended their practice to include aspects such as tube replacement and unblocking tubes. Gilmour and Glencourse's (1998) survey from over ten years ago suggested that a minority of UK dietitians took on an expert role when they took sole responsibility for the formulation of parenteral nutrition.

There are no studies specifically describing British dietitians undertaking the roles of educator or advocate. However, as outlined in the literature review, various British guidelines and standards suggest that dietitians should be undertaking the role of an advocate (The British Dietetic

Association, 2008a; The Scottish Government, 2012; The British Dietetic Association, 2013; Health and Care Professions Council, 2016).

The literature on the roles of dietitians from America, Canada, New Zealand and Australia supports my data on the role of expert and educator (Marquis and Gayraud, 2002; Wassink and Chapman, 2010; O'Sullivan Maillet *et al.*, 2013; Brody *et al.*, 2014; Milosavljevic *et al.*, 2014; Szeto *et al.*, 2014). However, the role of advocate has not been fully described within dietetic practice before, although it has been noted as a skill that dietitians require (Dowding *et al.*, 2011; Holliday *et al.*, 2013; O'Sullivan Maillet *et al.*, 2013; Brantley *et al.*, 2014; Brody *et al.*, 2014; Mondelli *et al.*, 2015). Specially within decision-making about ANH, advocacy may be required (Fairclough *et al.*, 2008; Jenkins, 2012; Nelson *et al.*, 2015). This is the first study to report dietitians actually taking on an advocacy role within the provision of ANH.

'Technician'

Dietitians also undertook the role of technician, where they implemented the decisions of others. This might be viewed as what Freidson refers to as a 'subordinate position' (Freidson, 2013:90), especially if the dietitians have not been involved in the actual decision to start ANH. However, this technician role is an area that dietitians have discretionary judgement over. They make autonomous decisions about type, amount, duration, and volume of feed; they used their skills and expertise, for example, in calculating requirements and deciding on a suitable feed, so it is an

important part of professional practice. Dietitians performing a technician role has not been reported in the literature before now. The reasons why dietitians were being used as technicians and were not more directly involved in the decision-making process was not explored in this study; however, there are a number of possible explanations. As this is important for the professional role of a dietitian, these will now be considered.

Dietitians may have been used as technicians because they were not perceived as experts and so may not have been seen as having a role in decision-making: their role may have been perceived as only being concerned with the technical aspects of feeding, such as calculating requirements and deciding on a feeding regimen. While there is no UK research in this area, there is some international evidence to support this view. The Thoresen *et al.* (2008) survey of Scandinavian dietitians suggested that dietitians are not always acknowledged as experts. A survey of American dietitians by Rylander *et al.* (1997) reported that doctors were not accepting of dietitians' involvement in complex decision-making related to ANH, and Stamp *et al.* (2013) reported that American doctors only implemented 39% of dietitians' recommendations. A mismatch in role perception was reported by Gaare *et al.* (1990) where American dietitians saw themselves as the primary decision maker over half of the time, but doctors only regarding them as such about 10% of the time. This has the potential to affect professional relationships and have negative effects on team working (Freeman *et al.*, 2000). This mismatch in role perception may be related to the role of the dietitian not being

understood. American and Australian surveys with other professionals concluded that dietetics was a small profession, and the role of a dietitian was not fully understood by other team members (Thomas *et al.*, 2006; Mitchell *et al.*, 2012). Therefore, Thomas *et al.* (2006) suggest that there needs to be a greater appreciation of the role of the dietitian within healthcare teams. Indeed, a survey of American doctors concluded that dietitians needed to educate doctors more about their role (Hart *et al.*, 1997). While these are international studies where dietetic practice and healthcare structures may be different to the UK, the British Dietetic Association also seems to recognise that dietitians need to promote their role more and have produced an 'influencing action pack' (The British Dietetic Association, 2015b). This pack aims to promote the role of the dietitian to key stakeholders

Another reason why dietitians were used as technicians may be because the decision was made before a referral to a dietitian, perhaps because the dietitians were not present on the wards and so were unavailable to be included in discussions when decisions were made. While not specifically looking at dietitians' involvement in decisions, Thoresen *et al.*'s (2008) survey of Scandinavian dietitians concluded that when dietitians had a greater presence on the wards there was a better focus on nutrition support. This may have knock-on effects of including dietitians in decisions.

Dietitians may also have been used as technicians because nutrition was not seen as being important. Of course, if a decision was made, nutrition

must have been considered to some degree, but if it is not highlighted by the team then decisions may be made as an afterthought or made late and only after a patient has become obviously malnourished. My data does suggest that nutrition was not always seen as a priority, as illustrated by the need to advocate for nutrition and dietetic services, and the battles some dietitians had for patients to be fed. (This will be discussed further with the next theme in section 8.2.2.) The literature also supports the view that nutrition itself may not be a priority for some healthcare teams.

Research suggests that Swedish nurses saw nutrition as a low priority, and even after training they did not fully understand their responsibilities for nutritional care (Bjerrum *et al.*, 2012). In Denmark a survey of nurses who worked with older people reported that nearly half of the nurses surveyed were indifferent or had negative attitudes to improving nutrition (Bachrach-Lindström *et al.*, 2007). In a study reporting American dietitians' views of critical incidents, nurses were cited as a common barrier to implementing nutrition support activities (Marquis and Gayraud, 2002). Two UK surveys of nurses reported that nurses have poor knowledge about nutrition support (Perry, 1997a), and do not carry out nutrition support behaviours such as weighing patients (Perry, 1997b).

Although some of these studies are old, and others give an international perspective, there is some evidence to suggest that problems still remain in the UK. The UK policy of protected meal times, where all ward staff should focus on mealtime and feeding patients who need assistance, is not well adhered to (The National Reporting and Learning Service, 2007;

Connolly *et al.*, 2011). Many of these aspects were described in my participants' accounts. Overall, nutrition is not always accepted as important and has a low priority in many settings (Care Quality Commission, 2011; BAPEN, 2012; Russell and Elia, 2012). With the implementation in 2014 of standard 14, 'meeting nutritional and hydration needs' of the Health and Social Care Act (The Care Quality Commission, 2008), it is possible that the profile of nutrition will improve.

These varied roles had a large influence on the dietitians' lived experience of involvement in decisions related to ANH. The role of expert and advocate was part of many of my participants' professional identity and not being recognised as such created challenges for their professionalism. The need to advocate for dietetic services suggests that there may be some issues with the status of some dietitians which can have professional implications. How these roles link with having an influence on decisions will be considered in the discussion of the next theme.

8.2.2 'Wanting to be heard'

The theme 'wanting to be heard' revealed that my participants wanted to be involved in decision-making about ANH and illuminated the efforts and approaches the dietitians took to try to be heard. It also highlighted their desire for professional autonomy, that is, the ability to make decisions and act on professional knowledge (Molleman *et al.*, 2008), as they all wanted to be involved in decision-making. 'Being known', 'making a difference', and 'speaking up' appeared to facilitate dietitians to be heard. However,

some described feeling 'silenced' during decision-making, as they did not have the clinical information they needed to fully contribute. An analysis of the theme 'wanting to be heard' may reveal how dietitians can be recognised as having a role in decision-making about ANH, thus improving their professional status.

'Being heard'

'Being known' by the team and 'making a difference' to care helped my participants to be heard during decision-making, but these were both achieved by 'having a presence' in the clinical setting. Communication skills, team working, building relationships, experience, and confidence were also important for this. The roles of expert and advocate, which included percutaneous endoscopic gastrostomy (PEG) counselling, involvement in best interest decisions, and drawing up advance directives, enabled my participants to show their expertise to others. These may have contributed to them being seen as an expert and therefore included in discussions and decisions about ANH. The role of educator may also have contributed to them 'being heard'. Freeman *et al.* (2000) suggested that education is more readily accepted from peers or supervisors than from those of a perceived lower status, so when doctors accepted education from dietitians it may have been because they were seen as knowledgeable.

To take on the advocate role, my participants needed to feel able to influence a decision, and to have the confidence to speak up. Dietitians in

my study described acting as advocates during face-to-face contacts, during team interactions, and in multi-disciplinary team meetings. Team discussions were an important forum for my participants to show their expertise and their knowledge of patient preferences. This allowed them to be heard and to influence decisions. Therefore, having a presence in clinical situations was needed to take on this role which facilitated 'being heard'. This was identified as important as far back as the late 1990s in a discussion paper by the American dietitian Kent (1997) who was of the view that doctors prefer dietitians to be available on the wards in order to have face-to-face discussions about patients. Therefore, having a presence in the clinical setting and having time to attend meetings is likely to be important in order to be heard.

Many dietitians seemed to be successfully involved in decisions: they were heard. For them, this meant having their view heard and respected, but not necessarily having their view accepted and adopted. Feeling respected was an important part of their lived experience. Some dietitians seemed to demonstrate power in order to be heard, an important aspect of professionalism (Van De Camp *et al.*, 2004). Expert power was illustrated when the dietitians were accepted in the expert role, during the education of others, and during advocacy roles.

'Not being heard'

While some dietitians, in some situations, seemed to have power to be heard during decisions about ANH, not all participants did. There were

many accounts of feeling that their opinion did not count when decisions were made. There were also many situations when decisions were made about ANH without including the dietitian. This led to some feeling frustrated, undermined, and dissatisfied, suggesting powerlessness. Again this created a challenge for dietitians' professionalism, clearly articulated by senior acute care dietitian P11 in section 6.2, *'I feel undermined...what's the point of me being here with this profession?'*

It seems that organisational factors were linked to my participants' lived experiences of involvement in decision-making about ANH, as they needed a presence in the clinical setting in order to be heard during decisions. Being short-staffed or having a heavy workload may have meant that the dietitians' physical presence in clinical settings was reduced. For some of my participants, workload pressures had a negative influence on the ability to attend team meetings or ward rounds. If dietitians do not attend meetings it will be harder for them to be known and develop relationships, to get all the information they need for decision-making, to show that they can make a difference, and it can be harder to communicate with the team. In my research it was mainly junior dietitians who expressed difficulties with time pressures. This may have an effect on professional practice and patient care. Thoresen *et al.* (2008) recommended that a dietitian needed to attend a ward at least three times per week in order to positively influence malnutrition in a clinical setting.

While not being able to attend the meetings can be disempowering, there is evidence to suggest that attendance at meetings can be positive. Cook *et al.* (2001) evaluated inter-professional working within two services in the UK and concluded that attendance at multi-disciplinary team meetings can empower. Attendance at meetings may have a positive influence on team working and may help to break down hierarchies and create an inclusive team culture by having shared goals for patients (Clarke, 2010). Indeed, various recommendations have been made for American dietitians to have a presence at meetings to improve team working (Kent, 1997; Dahlke *et al.*, 2000; Kushner *et al.*, 2007). However, attendance at team meetings is just part of the process of enabling dietitians to be included in decision-making and to raise their profile: relationships with doctors and other team members also appear to be important for dietitians. Szeto *et al.* (2014) reported that the Canadian dietitians who responded to their survey stated that the dietitians who had a positive relationship with physicians had a more extensive role in decision-making compared to others. Qualitative research with American dietitians conducted by Dahlke *et al.* (2000) suggests that those who actively collaborate with the team and are proactive, rather than reactive to doctors' requests, experience an increase in their profile and ability to have an influence. Leonberg (2007) believes this can aid decision-making, as dietitians who work closely with doctors are more likely to receive greater professional authority from the doctors.

Nurses' experiences of being involved in decision-making resonate with my participants. Bryon *et al.*'s (2008) systematic review suggests that nurses have varying levels of involvement in the decision-making process, with direct involvement being limited. Other research highlights conflict between nurses and doctors related to decision-making, with nurses feeling that they were unable to influence the decision-making process (Uden *et al.*, 1992; Oberle and Hughes, 2001). Some nurses felt powerless (Uden *et al.*, 1992) and some followed the doctor's orders regardless of whether they agreed or not (Jansson and Norberg, 1989; Day *et al.*, 1995). Some nurses were unable to act as advocates for patients because they believed that they were not viewed as part of the team (Bryon *et al.*, 2012a). Not being able to advocate for patients can lead to moral distress for the nurses (Austin, 2012). (Reasons for moral distress in my participants will be considered in the discussion of the next theme.) It should be noted that some of this literature of nurse experiences is non-UK based and was conducted before nurses took on more specialist roles, and recent research from Facklet *et al.* (2015) suggests that nurses are now more empowered.

Qualitative research of nurses' experiences from Canada, Ireland, Australia, and Korea concluded that when professions believe they are undervalued, relationships and job satisfaction can be negatively affected (Malloy *et al.*, 2009). This feeling of dissatisfaction is important as it has the potential to affect both patient care and the health professional. Thomas (2004) suggests that a feeling of dissatisfaction is linked with a

feeling of powerlessness. Within nursing, survey and qualitative research suggests that job dissatisfaction is associated with poor job performance, reduced quality of care, and increased risk of burnout (Billeter-Koponen and Fredén, 2005; Sheaff, 2005; Faulkner and Laschinger, 2008). For Australian dietitians recognition was one of the factors identified as important for job satisfaction (Cody *et al.*, 2011). Thomas (2004) noted that nurses who believed they were not respected and were undermined experienced feelings of anger. Rose and Glass (2006) conducted qualitative research with Australian mental health nurses, which identified a link between emotional well-being and effective professional practice. Some of my participants described feeling anger, feeling undermined, and feeling frustrated. These will be considered more fully in the discussion of the next theme.

For my participants, their lived experience of 'being heard' during decisions about ANH was varied. Some seemed to be respected and listened to, which was a positive experience for them, although at other times their voices appeared not to be heard. At times, some dietitians appeared to be powerless to influence decisions. Dietitians were more likely to be heard when they were known by the team and were seen to make a difference to care. When the dietitians were not known by the team, it was harder to be heard. When dietitians were not heard and did not agree with the decision made, they seemed to feel frustrated, undermined, felt a lack of respect for them as dietitians, and felt

dissatisfaction with their job. This will be discussed further in the next section in the analysis of the theme, 'The emotional roller coaster'.

8.2.3 'The emotional roller coaster'

The 'emotional roller coaster' revealed the complex and intense emotions experienced by the participants during their work within ANH. Sometimes these were caused by situations being emotionally difficult, for example, when dealing with end-of-life decisions. However, they were also caused by the dietitians' roles and their attempts at trying to be involved in decisions, as described above. They felt proud when they believed that they had done a good job. They felt angry when patients had not been treated as they believed that they should or when family pressure influenced ANH decisions in a way they did not agree with. They felt guilt when there were problems associated with ANH, for example, patients developing diarrhoea, which is often blamed on the feed. They felt unsure when it was not clear what to do, for example, when tubes became dislodged, or it was not clear whether a patient wanted ANH, or when it was unclear whether ANH was of benefit. Some appeared to describe moral distress when they were unable to influence a decision they morally disagreed with, for example, when ANH was provided to a patient that they believed had a poor quality of life or who was suffering. So not being heard or involved in decision-making had an emotional cost for some.

The data in this study illustrates the range of emotions described by my participants during their accounts of involvement in decision-making about

ANH. While positive and negative emotions related to clinical practice have been described by American dietitians (Marquis and Gayraud, 2002; Devine *et al.*, 2004), the detail of the type of emotions encountered in relation to decision-making about ANH has not been described until now. The emotions my participants experienced seemed to be rooted in their desire to do the best for their patients. For them, their professional identity of being a good dietitian seemed to be more than just being a technician and providing the correct nutrition. It was about trying to understand their patients' needs as a whole. When they felt they had done a good job they had a positive experience, but when they felt uncomfortable with the situation or decision, their emotional experiences seemed to be negative.

Positive emotional experiences

My participants described positive emotional experiences of being involved in decisions about ANH when they felt they had done a good job. These experiences were mainly related to being committed to doing their best, feeling proud to be a dietitian, feeling proud to do an important job, and making a difference to patient care. They also felt proud when others showed them respect. All of this suggests high job satisfaction for many of my participants. Similar positive experiences have been found in studies of dietitians in different contexts. Devine *et al.* (2004) reported similar findings in their qualitative research with American dietitians. Good experiences were related to positive interactions with others, clinical improvements for their patients, recognition of their expertise, and feeling that people were being helped and disease prevented. Marquis and

Gayraud (2002) also reported similar results for their cohort of American dietitians: good experiences were related to the feeling that they had a positive effect on care, when they undertook teaching and training, and when their advice was seen as credible.

Negative emotional experiences

The negative emotional experiences my participants described as part of their lived experience of involvement in decisions about ANH appeared to be related to their professional identities of expert and wanting to do the best for their patients. My participants described feeling anger when their concerns about patients were not taken seriously, and when nutrition support was not taken seriously, as they wanted their patients to get the best care. They seemed to feel anger when their expertise was questioned as it clashed with their professional identity of being an expert. They seemed to believe that their advice should at least be listened to, as they were professionals. As experts they described feeling troubled when things did not go to plan, for example, when patients receiving ANH vomited. They felt responsible for problems, even when it was out of their hands, for example, feeling responsible that a patient could no longer go home because they had a PEG, or that providing ANH may lead to what they believed was a poor quality of life. My participants wanted to do their best for patients and they appeared to be troubled when the right thing to do was unclear in some situations. Repassing tubes, decision-making on behalf of patients who lacked capacity, and feeding when it was believed

that patients had a poor quality of life were all situations which seemed to be problematic for many of them.

The term moral distress refers to the emotional response experienced as a result of doing something believed to be wrong (Jameton, 2013). An important finding of this research was that a few participants seemed to experience moral distress, which has not been reported in literature regarding dietitians before now. The situations in which moral distress was experienced varied. They included feeding when participants believed that the patient had a poor quality of life or was at end-of-life and treatment should be withdrawn, inappropriate PEG placement when the dietitian did not believe it was indicated, and feeding without adequate blood results. It was not clear whether these dietitians spoke up against decisions and tried to influence a decision or whether they felt powerless to do so.

However, courage is needed to be able to stand up to medical dominance in these situations. While the Health and Care Professionals Council code of conduct for dietitians states that dietitians can decline requests for interventions (Health and Care Professions Council, 2013), some of my participants expressed concerns that if they did not provide treatment to their patient then someone less qualified may do it. This did not align with their professional value of wanting to do the best for their patients.

Certainly in some situations, the moral distress seemed to be related to undertaking a technical role, implementing a decision that others had made, often when patients were receiving long-term feeding. Some participants believed that ANH could not be withdrawn, and some

expressed concern about speaking up about their objection to feeding, as they believed that it might lead to professional censure.

Research with other professional groups supports my findings of moral distress associated with ANH. Moral distress related to ANH has been reported in nurses and doctors in a number of studies (Uden *et al.*, 1995; Norberg *et al.*, 1998; Oberle and Hughes, 2001; Ferrell, 2006; Mobley *et al.*, 2007; Austin *et al.*, 2009; Bryon *et al.*, 2012b). In her discussion paper on moral distress, Austin suggested that it is a 'contemporary plight of health professionals' (Austin, 2012:28). In another discussion paper introducing the concept of moral distress, Pauly *et al.* (2012) were of the view that moral distress was related to having difficulties in upholding professional values and responsibilities and can lead to a decrease in job satisfaction. In a systematic review of nurses' experiences of moral distress, Huffman and Rittenmeyer (2012) concluded that institutional constraints, how well nurses believed that they could advocate for their patients, a lack of influence on decision-making, and a lack of recognition of their expertise all contributed to the nurses' moral distress. These resonate with my participants experiences. Worryingly, nurses also reported anger, loneliness, depression, guilt, powerlessness, and emotional withdrawal from patients and within themselves, which could affect patient care (Huffman and Rittenmeyer, 2012). McCarthy and Gastman's (2015) review of discussion papers about moral distress in nursing concluded that, overall, moral distress was likely to have a negative effect on nurses personally and professionally, and can harm

patients. Therefore, it is possible that moral distress in my participants could affect them and their patients.

Within the dietetics literature, while there are some similarities in negative emotions, most of my findings are in contrast to the negative experiences reported by American dietitians in the studies by Devine *et al.* (2004) and Marquis and Gayraud (2002). For the dietitians interviewed by Devine *et al.* (2004) their negative experiences were varied. These included a lack of understanding by others of how dietitians worked: difficulties with meaningful outcome measures within dietetics, often due to the lack of time that the dietitians had with patients to make meaningful changes, for example, the time needed to show weight changes or improvement in biochemical measures like cholesterol or glucose levels. Negative experiences also included a lack of respect from colleagues, difficulties with keeping up-to-date, feeling professionally isolated, difficulties with team working, and difficulties with food choice for patients. Interestingly, in Devine's qualitative study the authors stated that the dietitians were more comfortable with the term 'challenges' rather than 'frustrations' as they suggested that frustrations were just part of being a dietitian. The authors quoted one dietitian as saying frustrations are 'inherent in all parts of being a dietitian' (Devine *et al.*, 2004:798). However, not all the dietitians they interviewed accepted these 'challenges': some moved jobs as the conflicts were too difficult to cope with. For the dietitians in the study reported by Marquis and Gayraud (2002), negative experiences were related to role and interpersonal conflict, lack of communication, complaints, hierarchy,

lack of interest from patients, lack of confidence on behalf of the dietitian, and a lack of respect, leading to feelings of low self-esteem and a lack of credibility.

Within the dietetics literature, three studies have reported levels of dietitians' emotional exhaustion as part of investigations into dietitians' risk of burnout. Emotional exhaustion has been defined as the feelings of being overextended and exhausted by work (Milosavljevic and Noble, 2014). The studies reported moderate levels of emotional exhaustion among Australian (Milosavljevic and Noble, 2014), Canadian (Gingras *et al.*, 2010), and American dietitians (Kolodny and Chan, 1996) with levels highest in full-time workers and those in more senior levels. The reported levels were similar to those seen in doctors but lower than nurses. While emotional exhaustion was not specifically examined in my research, the findings regarding emotional exhaustion do support the view that dietitians work in emotive settings and have emotional experiences.

My participants' lived experience of involvement in decision-making related to ANH included a range of emotions. These included positive and negative experiences, and often their professional identity as experts influenced these emotions. Positive experiences were related to being respected, while negative experiences were related to not being heard during decisions, feeling undermined, and disrespected. Moral distress was primarily associated with feeding patients that participants believed should not be fed. Strong emotional experiences require coping strategies

and support to enable healthcare professionals to fulfil their role, care for their patients, and avoid burnout. How dietitians respond to these emotional experiences will now be discussed.

8.2.3.1 Responding to emotions

The data suggested that the participants responded to the 'emotional roller coaster' by 'not showing their emotions', by 'keeping a distance', by 'becoming desensitised', by 'speaking out', and by 'getting support'. They modified what they showed of their emotions when they seemed to be troubled by them. They appeared to respond by not showing their emotions in front of patients, for example, when colleagues had put them in difficult situations. Some seemed to physically or emotionally distance themselves from difficult situations. By reflecting on their experiences, some acknowledged that they had become desensitised to some of the emotional situations related to the provision of ANH. Some seemed to respond by speaking out in order to protect their patients. All described how they needed support from colleagues, but time for practice supervision was sometimes difficult. The participants seemed to try to moderate their emotions in order to protect their patients, their colleagues, and themselves. This moderation of emotions often had an additional emotional cost for them as professionals, suggesting that it may not be an effective way to manage their emotions.

Healthcare professionals need to respond appropriately to their emotional experiences, and discussion papers have encouraged American dietitians

to develop their emotional intelligence: that is, recognising and regulating emotions in order to work effectively in teams (Leonberg, 2007; Escott-Stump, 2011; Fox, 2013). The Dietitians Association of Australia (2015) competencies for entry into the profession include the ability to be able to manage one's own emotions, but they do not elaborate further on what may need to be managed and what would be professionally acceptable or unacceptable. Marquis and Gayraud's (2002) survey of Canadian dietitians suggested that these dietitians needed to manage their emotions, but they did not give any recommendations about how this should be done. Therefore, research on how dietitians respond to their emotions has been lacking until now.

Emotional labour

The way some dietitians seemed to respond to their emotional experiences of involvement with ANH decision-making appeared to suggest that they undertook emotional labour as part of their lived experience. This is a key finding, as emotional labour has not been reported as a concept within dietetics before now. As outlined in the literature review, Hochschild (2012) first coined the phrase emotional labour which she defined as 'the management of feeling to create a publicly observable facial and bodily display' (Hochschild, 2012:7), and that it requires the inducement or suppression of feelings 'in order to sustain the outward countenance that produces...the sense of being cared for in a convivial and safe place' (Hochschild, 2012:7).

It may be expected that dietitians experience emotional labour as they often work with patients face to face, they may see patients who are experiencing psychological distress, and dietitians have to conform to codes of conduct (Kirk *et al.*, 2000; Health and Care Professions Council, 2013; Health and Care Professions Council, 2016). The experiences my participants described, such as hiding emotions, seem to fulfil the criteria for emotional labour. The types of situations in which my participants described emotional labour (that is, hiding their emotions) were varied. These included when they were in difficult situations not of their own making, when they felt frustrated with patients, when they felt sad about a clinical situation, and when they hid how they felt because of their faith or values. The dietitians seemed to believe that showing these emotions would be unprofessional, therefore emotional labour could be viewed as being linked with their professionalism.

The emotional labour, which my participants seemed to undertake, was also related to hiding their feelings about patients receiving ANH who they believed had a poor quality of life. Emotional labour related to this has not been reported in dietetics before now. Some studies refer to the fact that dietitians are uncomfortable in these situations, but this has not been linked to emotional labour. A survey of Irish dietitians reported that 50% of the surveyed dietitians would not provide ANH to patients with dementia because it would not improve quality of life (Healy and McNamara, 2002). In a series of studies by Brotherton, 5% of paediatric dietitians believed that their patients did not have an acceptable quality of life and they would

stop feeding if they were given the choice (Brotherton *et al.*, 2007a), 30% of community dietitians believed that their patients did not have an acceptable quality of life, and 20% would stop feeding if they were given the choice (Brotherton *et al.*, 2007b). So while these studies do not report that the dietitians undertook emotional labour in these situations, their feelings related to ANH had resonance with many of my participants, as they too believed that some patients receiving ANH had a poor quality of life.

As previously stated, definitions of emotional labour have developed over time and there are also the associated terms of 'emotion work' and 'emotional work' (Smollan, 2006; Goodwin, 2011; Wang *et al.*, 2011). The definition I used was presented by Grandey (2000) which stated that feelings are regulated for organisational goals. This fits with some of the emotional labour that my participants seemed to undertake in their work related to ANH, for example, they were careful what they said about colleagues. However, some dietitians regulated their emotions because they were fearful of professional repercussions for themselves. Therefore, for my participants emotional labour was used in order to protect their patients, their colleagues, and themselves, which is a broader description of emotional labour than has previously been described. This develops the concept of emotional labour within dietetics, to give a broader definition of emotional labour specifically for dietitians. The importance and implications of this for practice will be discussed later.

Benefits and drawbacks of emotional labour

There are both potential benefits and drawbacks of emotional labour in healthcare. Undertaking emotional labour suggests emotional intelligence, that is, being aware of the need to show appropriate emotions within the workplace, which some suggest is key for team working (Smollan, 2006; Rankin, 2013). Emotional labour may have beneficial effects on relationships with colleagues and patients, and for the quality of care, and so may have a therapeutic benefit (Gray, 2009). Emotional labour may enable better care to be provided by enabling healthcare professionals to cope with the stress related to providing healthcare (Grandey, 2000; Lovell *et al.*, 2009). Empathy has also been a focus of comment about emotional labour, as it has been suggested that empathy can enable demanding or challenging relationships to be sustained (Hunter and Smith, 2007; Abbott Moore, 2010). Within medicine some review articles suggest that there can be challenges to showing empathy due to factors such as work pressures, and empathy can reduce over time (Larson and Yao, 2005; Burks and Kobus, 2012). Larson and Yao's (2005) discussion paper suggests that if doctors became skilled in emotional labour it would enable them to engage more effectively in showing empathy. Therefore, undertaking emotional labour may be beneficial for patient care, as it may enable better patient contact and hence allow the care to be more patient-centred (Gray, 2009). Indeed, qualitative research with Australian nurses conducted by Pisaniello *et al.* (2012) suggested that nurses' emotional labour led to greater patient satisfaction.

For the health professional trying to modify their true emotions, effort is required, as implied by the term 'labour' (Goodwin, 2011). The amount of effort required and the effect it has on the health professional is likely to depend on whether 'surface' or 'deep' acting is being used. Hochschild (2012) defined surface acting as the ability to deceive others about how we are feeling without deceiving ourselves, that is, faking it. Deep acting was defined as being able to deceive oneself and others about our true emotions by exhorting the required emotion, that is, similar to method acting (Hochschild, 2012).

Long term, it is surface acting which seems to have a negative effect on the health professional as it can lead to emotional dissonance, which is the strain of having to show an emotion which is not felt (Ashforth and Humphrey, 1993; Morris and Feldman, 1996). In a review of the literature on the effects of surface and deep acting, Goodwin (2011) concluded that surface acting was, overall, negative, as it could result in burnout, emotional exhaustion, decreased job satisfaction, and depersonalisation, which was likely to affect patient care. In contrast, deep acting could have neutral or even positive effects on job satisfaction and feelings of personal accomplishment. Hochschild (2012) suggests that deep acting can be learnt through training.

It seems likely that my participants used surface acting during their emotional labour, as the emotional labour they undertook was related to hiding their emotions. The response some participants had, feeling that

they were letting down their high personal and professional standards, also suggests surface acting rather than deep acting. If the surface acting continued for any length of time, there may be long-term effects for the patient and dietitian.

Distancing and desensitisation

A further important facet of dietitians' lived experience of decision-making relating to ANH was that some dietitians responded to their emotions by physically and emotionally distancing themselves from the emotional situation and by becoming desensitised to emotionally difficult situations. While the distancing enabled some participants to cope with difficult situations, some did feel uncomfortable about doing it. Distancing from difficult emotional situations in order to manage emotions has not been described in dietetics before, but has been noted in research with Canadian nurses (Miller *et al.*, 2008; Wassink and Chapman, 2010; Varcoe *et al.*, 2012b). Distancing has also been described within medicine. A survey of Spanish doctors exploring burnout reported that doctors distanced themselves from difficult situations (Moreno-Jiménez *et al.*, 2008). A survey of Canadian doctors conducted by Lee *et al.* (2010), which explored emotional expression and shared decision-making, also noted that some doctors distanced themselves from patients.

As previously stated, three studies have investigated dietitians' risk of burnout (Kolodny and Chan, 1996; Gingras *et al.*, 2010; Milosavljevic and Noble, 2014). As part of this, an assessment of depersonalisation, 'the

level of uncaring or unfeeling the employees may have towards their clients, was undertaken (Milosavljevic and Noble, 2014:2). The findings were similar to those for emotional exhaustion, with moderate levels of depersonalisation reported among Australian (Milosavljevic and Noble, 2014), Canadian (Gingras *et al.*, 2010) and American dietitians (Kolodny and Chan, 1996), with the highest levels reported in full-time workers and those in senior levels. Again, the reported levels were similar to those seen in doctors but lower than nurses. While these studies do not report that desensitisation occurred, the findings resonate with the accounts of desensitisation from some of my participants.

The experience of my participants becoming desensitised is consistent with reports of desensitisation in nurses (Hamric, 2012) and doctors (Monrouxe and Rees, 2012). Within medical students, Puchalski *et al.* (2014) described the difficulty students had with getting the right balance between desensitisation and supporting patients, which again resonates with the experience of some of my participants, as some felt uncomfortable that they were becoming blasé.

Responding to emotional clinical situations by distancing and desensitisation may be beneficial for the health professional. Burks and Kobus (2012) suggest that distancing may help health professionals cope with emotions, by enabling them to modify intense emotions which might otherwise be overwhelming. Mann's (2005) literature review led her to suggest that distancing can protect health professionals from becoming

too emotionally involved with their patients, so protecting them from stress. Hayward and Tuckey (2011) note that emotional distancing does not necessarily mean completely disengaging from patients: a clinical connection can remain, but emotional distancing creates an emotional boundary for the health professional. Thus, the health professional is more able to manage their emotions. It may mean that the health professional has greater emotional reserves which can be called upon in other situations (Hayward and Tuckey, 2011). A negative side to distancing was described within the context of paediatric palliative care by Liben *et al.* (2008) who suggested that having emotional boundaries can lead to communication difficulties, which can affect patient care.

Menzies' (1960) seminal paper exploring stress and anxiety in nurses described the need for professional detachment, in order to learn to control feelings. She suggested that as patient care had become more patient-centred there was likely to be greater stress and anxiety experienced, as the closer a health professional was to a patient, the more intense the relationship would be and so an increase in stress and anxiety would result. Sawbridge and Hewison's (2011) analysis of poor nursing care suggested that nurses need to develop professional detachment (or emotional boundaries) to still be able to show compassion and to reduce the risk of burnout. While the Sawbridge and Hewison (2011) report focused on acute nursing care, it did acknowledge that the findings may apply to other health professionals.

For my research a key aspect to consider is whether the distancing and desensitisation could have had a negative effect on patient care, and whether it affected the dietitian's ability to show compassion: an important issue given the recent scandals in the NHS, where some health professionals did not give their patients adequate care and compassion (Francis, 2013). However, as this research was broadly exploring the experience of involvement in decision-making and not specifically the care and compassion of dietitians, it is not possible to make a judgement on this.

Moral agency

A few participants who were experienced senior dietitians responded to their negative emotions by speaking out: they acted as moral agents. Moral agency is being able to think and act in a given situation and to take responsibility for that action (Carpenter, 2010; Lützén *et al.*, 2010). For the action to be moral, it needs to be grounded in professional or personal moral or ethical standards. 'Agency' suggests that the person acting has the ability to influence change (Edwards *et al.*, 2011). This is the first report of dietitians acting as moral agents, although it has been reported within physiotherapy, nursing, and genetic service providers (Geller *et al.*, 2009; O'Keefe-McCarthy, 2009; Edwards *et al.*, 2011). However, only a few of my participants responded to emotions by acting as a moral agents: for others it led to moral distress.

O'Keefe-McCarthy (2009) suggests that relationships with patients and the team are needed for moral agency, as the needs of the patient must be known and agency suggests influence with the team: it is therefore linked to professionalism (O'Keefe-McCarthy, 2009). Edwards *et al.* (2011) also link moral agency to professionalism from a 'social contract' point of view, that is, that professionalism needs to include meeting the aims of society, therefore health professionals need to speak out in order for the public to trust the profession. The profession needs to be viewed as trusted in order for the public to seek out that profession and to take their advice. To be a moral agent, the health professional's voice needs to be heard, thus in this research 'being heard' and the roles of 'expert', 'educator', and 'advocate' may all facilitate moral agency.

Support

The emotional situations that form part of my participants' lived experience of ANH led many to seek support, although many felt that there was not enough time for formal practice supervision. Support is important, as Smith (2012) suggests that for nurses, if support is not available, the emotional sensitivity of staff can be reduced. It may also lead to what the Health and Care Professions Council refers to as 'disengagement' in professional practice, which is not meeting professional standards of competency, which can affect patient care (Health and Care Professions Council, 2015b). The need for dietitians to have some kind of support through supervision or mentorship has been widely documented within dietetic practice (Burton, 2000; Kirk *et al.*, 2000; Mortensen *et al.*, 2002; Paulin,

2010; Hawker *et al.*, 2013). It has been suggested that as dietetics is a small profession, where dietitians may be working in teams without other dietitians, professional support may be particularly important (Paulin, 2010; The British Dietetic Association, 2012c). Osland *et al.* (2014) concluded from their survey of Australian dietitians that professional supervision might improve dietitians' professional quality of life. Support is also considered to be integral to ensure the delivery of a quality service (Kirk *et al.*, 2000; The British Dietetic Association, 2011). Therefore, support is a key aspect of professionalism.

Support can be provided in a number of ways. The British Dietetic Association advocates practice supervision of some form (for example, one-to-one or group) to support staff and enhance professional practice (The British Dietetic Association, 2011). Paulin's (2010) qualitative research with 20 New Zealand dietitians supports the view that supervision provides support and helps to maintain professional standards. Schwartz rounds are another way that staff can receive support. Schwartz rounds have been introduced to the UK as a way to support staff with the emotional and psychosocial challenges that may be encountered when caring for patients. They are similar to medical 'grand rounds' where a case is presented by staff, and they discuss their care, any challenges, and how they felt (Foster, 2015). Evaluation of the regular hour-long meeting for all staff involved in caring for patients indicates that they are valued by staff, that they have helped to strengthen team working, and that they have improved hospital culture by enabling more

openness and created a less hierarchical environment (Goodrich, 2011). While dietitians have been included in Schwartz rounds, generally their formal support comes from practice supervision.

8.2.4 Summary

To summarise, the lived experience of involvement in decision-making related to ANH suggest that while some dietitians were involved in decision-making, not all were involved in the actual decision to feed: they implemented the decisions of others. However, all dietitians wanted to be involved, and many had strong emotional experiences which they attempted to protect themselves from. Professionalism seemed to be an important aspect of the dietitians' lived experiences. The professional identity of my participants seemed to be one of being an expert and wanting to do their best for their patients to ensure holistic care. Advocacy for dietetic services and the promotion of the role of the dietitian within nutrition support suggests that for some the status of dietitians could be improved. Just providing ANH as a fuel to meet nutritional requirements was not the primary aim of care; my participants wished to provide appropriate ANH in their patients' best interests.

Professional autonomy was important for my participants, that is, the ability to make decisions and act on their expertise. Professional power was needed in order to be heard during decision-making about ANH. Emotions were often related to professionalism: they felt good when they believed that their input was positive and when they were respected as a

professional. They described negative emotional experiences when their professional expertise was not recognised. My participants had a desire to be involved in decisions and they believed that they should be involved because they understood their patients and thought they knew what might be best for them and were experts in nutrition. Some showed their professionalism by speaking out and acting as moral agents. Some described the way they responded to their emotions in terms of professionalism, as they believed that emotions should not be shown.

8.3 Conceptual framework of professionalism

Interpretive phenomenology aims to understand people's experiences (Harris *et al.*, 2009), and as professionalism seems to be intertwined with my participants' lived experiences of involvement in decision-making about ANH, I have used the conceptual framework of 'professionalism' to consider their experiences and the challenges to professionalism that dietitians may face. As previously discussed in the literature review, the threefold model of professionalism has been used to conceptualise professionalism across medicine (Van De Camp *et al.*, 2004; Hodges *et al.*, 2011), occupational therapists, podiatrists, and paramedics (Burford *et al.*, 2014), and dietetics (Marais *et al.*, 2012). It has been used to capture the views of students (Marais *et al.*, 2012; Burford *et al.*, 2014), educators (Burford *et al.*, 2014), and doctors from a range of career stages (Van De Camp *et al.*, 2004; Hodges *et al.*, 2011). Therefore, it was chosen as a framework to explore the findings of this research. The use of a conceptual framework enables the findings to be considered and for sense

to be made of them (Savin-Baden and Howell Major, 2013). Concept maps can facilitate this (Maxwell, 2013) and have been used to organise themes into a conceptual framework of professionalism (Figure 1). Concept maps can also help to conceptualise the challenges to professionalism and highlight areas for development within dietetic practice (Figure 2).

The concept map in Figure 1 demonstrates how the findings from this research link to professionalism. It shows the experiences which suggest challenges to professionalism and those which suggest professionalism. The subthemes which straddle the dotted line do so because they could relate to either demonstrating professionalism or challenges to professionalism.

Challenges and tensions in the experiences of involvement in decisions

Experiences suggesting professionalism during involvement in decisions

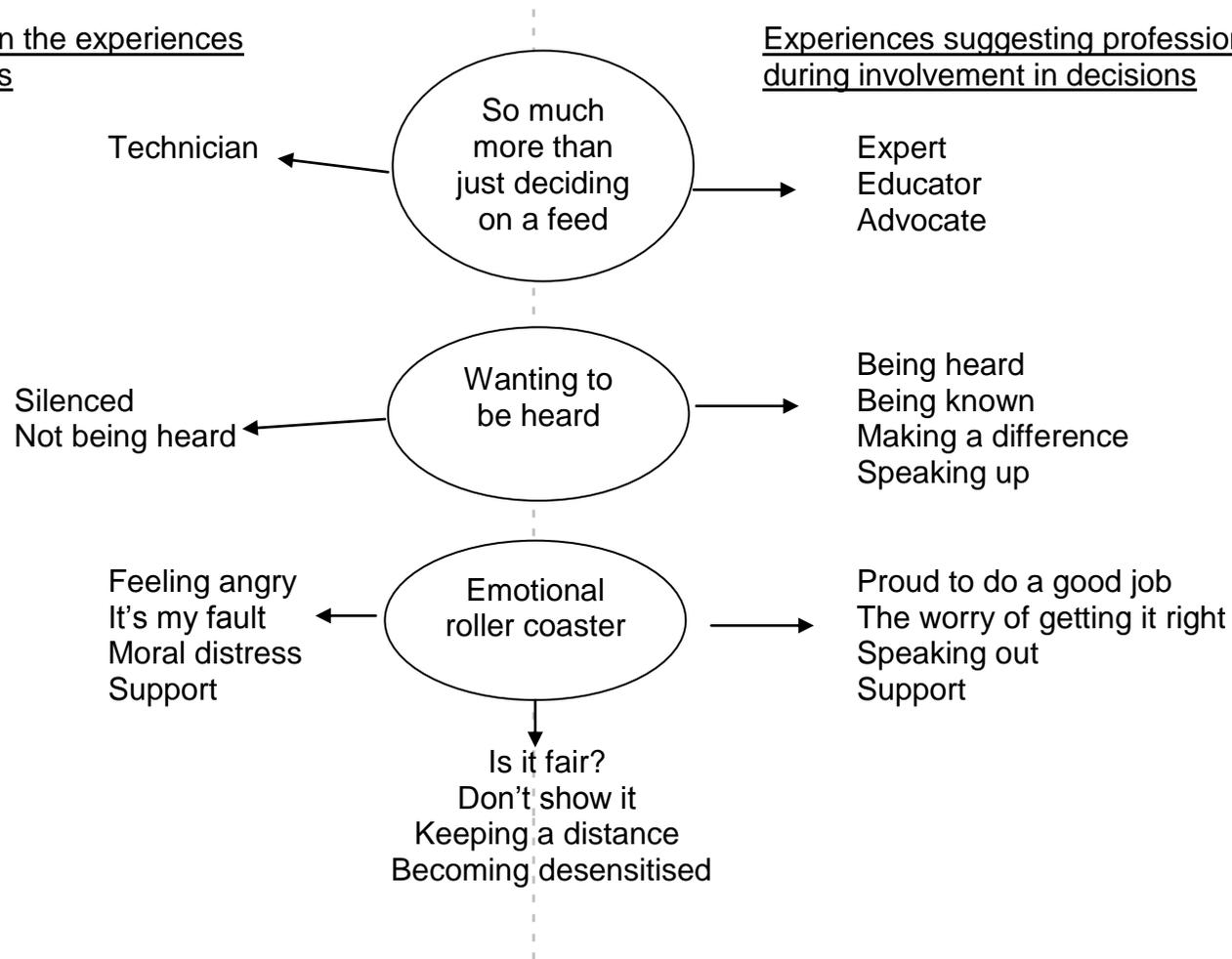


Figure 1 - Challenges to professionalism and experiences which suggest professionalism

The threefold model of professionalism is outlined in Table 5. This table also outlines how the experiences of my participants' involvement in decision-making map to these three principles and includes the challenges and tensions within their experiences in relation to professionalism.

The data suggests that the dietitians who participated in this study worked hard to try to demonstrate their professionalism, and often they were able to do this. However, as previously suggested, the picture was mixed, with some dietitians experiencing significant challenges and barriers to demonstrating their professionalism. To promote dietitians' professionalism during decision-making, an analysis of the challenges and tensions is needed. Addressing these challenges may have benefits for patient care and job satisfaction.

Using the threefold model, challenges to intrapersonal professionalism for the dietitians in this study appeared to be related to individual characteristics, such as the confidence to speak up, having emotional intelligence, and ethical principles. The data suggests that challenges to interpersonal professionalism were related to team characteristics, such as hierarchy, dietitians feeling a lack of respect, ethical principles, and the profile of dietetics and nutrition. It can be argued that challenges to public professionalism were related to a low profile of dietitians or confusion about the role of dietitians, and organisational and power barriers.

Table 5 - Threefold model of professionalism

Discourses of professionalism	Elements of professionalism	Principles and traits described by my participants
<p>Intrapersonal professionalism</p> <p>(Van De Camp <i>et al.</i>, 2004; Hodges <i>et al.</i>, 2011; Burford <i>et al.</i>, 2014)</p> <p>Meeting the demands to function in the profession as an individual; personal characteristics inherent or learnt.</p>	<p>Lifelong learning, maturity, morality, value dietetic work intrinsically, humility, critique, absence of impairment, good clinical judgement, response to stress, flexibility, virtue, motivation, appreciate literature and arts, goodwill, deal with uncertainty, critical analysis, not letting personal beliefs influence care, know limits of professional, humanistic values, being well-organised, courage, self-awareness, temperance.</p>	<p><u>Experiences suggesting professionalism</u></p> <p>Battling for patients Responding to emotions Working to try to not let personal beliefs influence decisions Emotional labour related to own values Moral agency</p> <p><u>Experiences suggesting challenges and tensions for professionalism</u></p> <p>Moral distress Not having confidence to speak up Challenges in responding to emotions Challenges of uncertainty encountered in some decisions View that ANH cannot be withdrawn</p>

<p>Interpersonal professionalism</p> <p>(Van De Camp <i>et al.</i>, 2004; Hodges <i>et al.</i>, 2011; Burford <i>et al.</i>, 2014)</p> <p>Meeting the demands for adequate contact with patients and other healthcare professionals; interactions with others.</p>	<p>Altruism, respect, integrity, service, honour, honesty, compassion, reliability, relationships with colleagues or team, interpersonal skills, communication skills, leadership, trust, educate patients, caring, avoiding misuse of power, admit errors in judgement, take time to complete work, ask help when necessary, not ripping people off, participation, response to instruction, tolerance, be sensitive, sensitivity to a diverse patient population, be thoughtful, treat patients politely, give information in a way patients understand, respect patients' right of shared decision-making, be responsive to patients' and colleagues' age, gender and disabilities, responsibility, suspension of self-interest, benevolence.</p>	<p><u>Experiences suggesting professionalism</u></p> <p>Acting as an educator Good communication skills Respecting and actively promoting patients' involvement in decision-making Trying to promote relationships with colleagues, the team and patients Working to be honest to patients about benefits and burdens associated with ANH Reminding patients (when appropriate) that ANH can be withdrawn Undertaking PEG counselling. Advocating for patients Empowering patients Moral agency Taking responsibility e.g. issues around consent and capacity and drawing up advance directives Emotional labour related to team working or patient contact</p> <p><u>Experiences suggesting challenges and tensions for professionalism</u></p> <p>Feeling a lack of respect from team members Hierarchies and feeling powerless Feeling undermined and frustrated when not listened to, heard or involved in decisions Concern about raising objections to providing ANH Low profile of dietetics</p>
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<p>Public or societal–institutional professionalism</p> <p>(Van De Camp <i>et al.</i>, 2004; Hodges <i>et al.</i>, 2011; Burford <i>et al.</i>, 2014)</p> <p>Meeting the demands society places on the profession; the profession as it is established in society. These may be team or organisationally-led and may be external to individual practice.</p>	<p>Accountability, submission to an ethical code/moral commitment, excellence, self-regulation, social contract, duty, high level of expertise, professional conduct, calling, negotiation, justice, method and thoroughness, clear professional values, understanding history, simplicity, faith in life’s meaning and value, use of explicit standards, deliverance of quality, professional awareness, technical competence, be knowledgeable, enhancing the welfare of the community, protect confidential information, carry out professional responsibilities, fight for and guarantee standards, commitment to continuity of patient care, adherence to guidelines, expert authority, transparent rules, autonomy of professional associations, commitment, whistle-blow if necessary, competence.</p>	<p><u>Experiences suggesting professionalism</u></p> <p>Role of expert Technical expertise PEG counselling Trust Professional and ethical values e.g. ensuring consent is obtained, advocacy Involvement in advance directives Working hard not to influence patients’ decision-making Moral agency/speaking up when believe that poor decisions had been made Battling for patients Wanting justice for patients, so they receive the best care Working to raise the profile of dietetics Gaining support</p> <p><u>Experiences suggesting challenges and tensions for professionalism</u></p> <p>Expertise not recognised Lack of trust Lack of understanding of the role of the dietitian Feeling of powerlessness Not speaking out about injustice The need to promote dietetic services Policies as barriers Organisational barriers to initiatives such as nutritional screening and protected meal times Organisational and professional display rules</p>
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An analysis of these challenges and experiences is illustrated in the final concept map, Figure 2. This also helps to illustrate new conceptual thinking about dietitians' experiences with reference to practical practice and professional development, plus the need for empowerment, knowledge of ethics, and development of emotional intelligence. These will be explored in the next section.

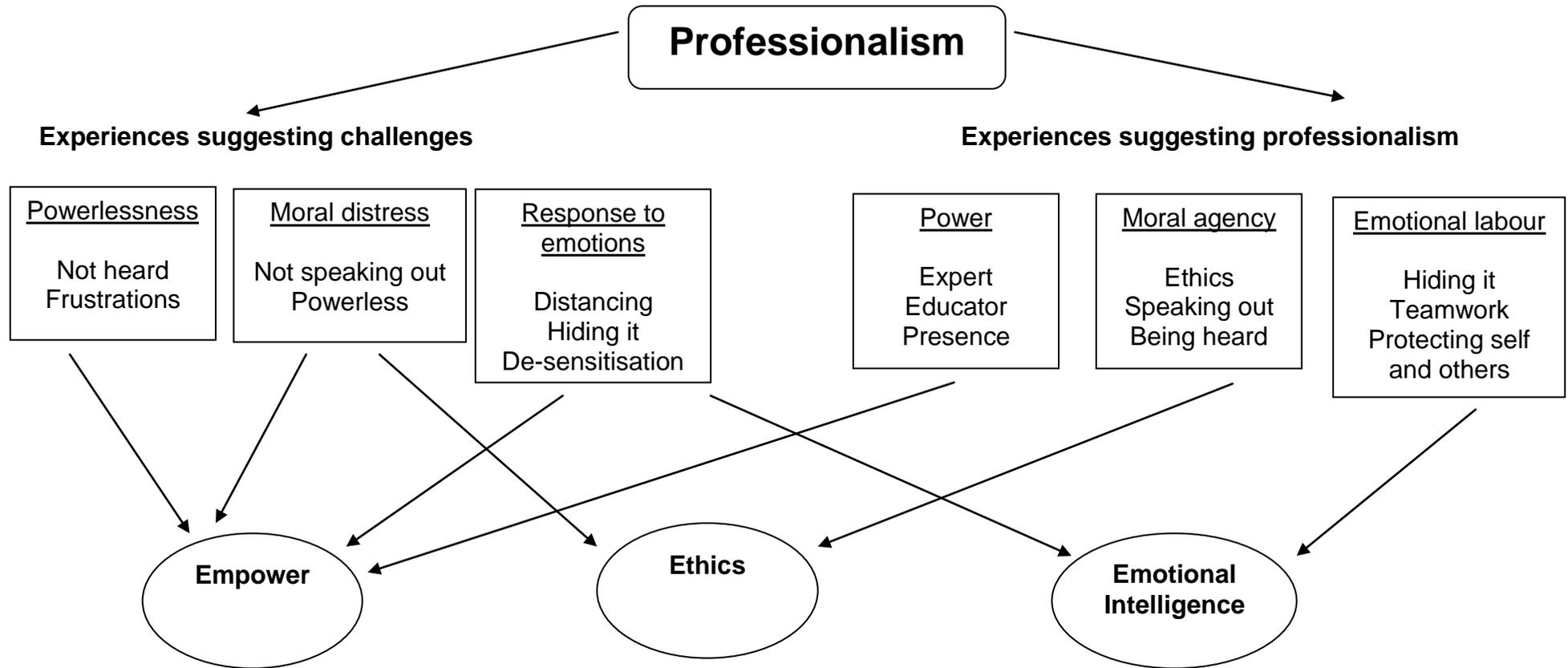


Figure 2 - Concept map to illustrate the main areas of professional development for dietetic practice

8.3.1 Empowerment of dietitians

While some individual participants in my research may not need to be empowered, the findings suggest that as a whole, professional empowerment may be needed. Indeed, empowerment of dietitians was the first strategic aim stated in the British Dietetic Association strategic plan for 2015-18 (The British Dietetic Association, 2015). Empowerment of American dietitians has been an aim of two past presidents of the American Dietetic Association (Edge, 2003; Bergman, 2012) with skills development recommended as the key to empowerment. However, the literature regarding the empowerment of nurses suggests that it takes more than just skills development to empower (Kuokkanen and Leino-Kilpi, 2001).

The empowerment of dietitians is directly related to the concept of professionalism, as empowerment enables autonomy, influence, and impact (Kuokkanen and Leino-Kilpi, 2000; Kuokkanen and Leino-Kilpi, 2001; Manojlovich, 2007; Bradbury-Jones *et al.*, 2008), therefore empowerment would facilitate having a voice during decision-making. The degree of autonomy that dietitians have over decisions about ANH has been previously discussed; however, what was key for my participants was being heard during the decision-making process. Therefore, empowerment should enhance their professional practice and professional development, and lead to better experiences by enabling them to be heard (Kuokkanen and Leino-Kilpi, 2000;

Kuokkanen and Leino-Kilpi, 2001; Faulkner and Laschinger, 2008; Wagner *et al.*, 2010).

As previously discussed, structural empowerment is enhanced by having adequate resources, support, access to information, and by having work opportunities in which power can be demonstrated (Wagner *et al.*, 2010; Trus *et al.*, 2012; Cicolini *et al.*, 2014). When structures support empowerment of professional practice, psychological empowerment can develop (Wagner *et al.*, 2010; Cicolini *et al.*, 2014). Psychological empowerment is enhanced by the feeling of having an important role, having autonomy and control over practice, and having a feeling of competence and confidence (Wagner *et al.*, 2010; Trus *et al.*, 2012; Cicolini *et al.*, 2014). Therefore, knowledge, support and feedback, resources (for example, time), formal power, and informal power from relationships with others are all needed for empowerment (Manojlovich, 2007; Spence Laschinger *et al.*, 2009; Wagner *et al.*, 2010).

This seems to fit with the dietitians who were able to influence decisions.

They were knowledgeable and demonstrated their knowledge to develop trust, they had support networks in place, they had the time to attend meetings and became known, and they developed relationships with the rest of the team.

All these aspects helped them to develop formal power, in this case their expert power, and their informal power through relationships.

The findings of qualitative research from Skipper and Lewis (2006) support this. These researchers interviewed 21 advanced practice dietitians from America and Canada to explore how these dietitians enhanced their autonomy. The main themes that the authors reported as important to enhance autonomy were education and experience which resulted in expertise, team working, collaboration, and being present when and where decisions were made.

Other authors have made recommendations about how to improve the status of dietitians, many of which are from America and many are discussion papers. A number of common themes emerge from this literature, which although originating from outside the UK may have some relevance to UK dietetics. The need to have a presence by attending meetings, to build relationships, and to be an active member of the team has been highlighted as important (Kent, 1997; Dahlke *et al.*, 2000; Peregrin, 2004; Kushner *et al.*, 2007; Leonberg, 2007). A second theme was the importance of showing that dietetic input can make a difference to care (Kent, 1997; Dahlke *et al.*, 2000; Dassenko, 2006; Leonberg, 2007). The third theme was the need to be proactive rather than reactive to doctors' orders and collaborate with the team (Dahlke *et al.*, 2000; Kushner *et al.*, 2007; Leonberg, 2007). Finally, educating the public, funding bodies, stakeholders, doctors, and the rest of the healthcare team about the dietitian's role to promote the role has also been noted as important (Feitelson, 1985; Burton and Freeman, 2005; Dassenko,

2006; Thomas *et al.*, 2006). The literature suggests that educating doctors about general nutrition is also required. Leslie and Thomas (2009) concluded that there was a lack of medical expertise and knowledge in nutrition. More recent surveys from America and the UK suggest that this continues to be an issue (Westfal *et al.*, 2011; Lane *et al.*, 2014). Leach *et al.* (2013) and Ray *et al.* (2013) suggest that the training of UK doctors may help to improve the profile of nutrition, and multi-disciplinary education programmes which include dietitians may promote effective team working (Ray *et al.*, 2012). It is interesting to see that Dutch dietitians have set up a website with a reference guide for doctors to inform them when they should be referring to a dietitian (Nederlandse Vereniging van Diëtisten, 2015).

Increasing public awareness of dietitians may also help it increase awareness of the role of dietitians and to promote nutrition. The British Dietetic Association has a national dietitian's week to raise the profile of dietetics, with the focus to 'Trust a dietitian'. Part of the reason for this focus on the public face of dietetics appears to be because often nutrition messages in the media are made by non-nutrition experts and result in mixed or inaccurate messages (McCullough, 2015). These mixed messages lead to the public being confused as to what to do and whose advice to follow (Goldacre, 2008). Within nursing, ten Hoeve *et al.* (2014), suggested that to empower nurses, they need to be more effective at communicating their professional roles.

These recommendations resonate with my research findings: the dietitians in my research who were heard during decision-making had a presence, were known by the team, demonstrated that their input made a difference, and educated other team members.

Team working seems to be an important aspect of empowerment (Laschinger and Havens, 1996; Kuokkanen and Leino-Kilpi, 2001; Faulkner and Laschinger, 2008), and is a facet of the conceptual framework of professionalism, therefore team working will be explored a little more in order to further consider empowerment of dietetics. Indeed, the role of allied health professionals within team working has been the focus of attention as reforms are made to the NHS and care is delivered in different ways by teams with different skills mixes and in different settings (Dorning and Bardsley, 2014; NHS England *et al.*, 2014; Swientozielskyj *et al.*, 2014).

Dietitians work in teams with other health professionals, so will be affected by hierarchy and power (Freidson, 2013). As healthcare has become more complex, there have been increasing divisions of labour, with different roles taken on by different professions. However, these are still subject to hierarchy, as professional norms, professional boundaries, and inter-professional communication will all have an impact on how well teams work together (Powell and Davies, 2012).

Dietitians working more in teams may help, as they would form relationships and be known. However, this may still cause conflicts and challenges if professional boundaries are contested (Freidson, 2013). For example, the dietitians interviewed by Stanley and Borthwick (2013) believed that the nutrition specialist nurses they worked with felt role boundary conflict when the dietitians extended their role to change feeding tubes. Others have reported that professional boundaries and hierarchies can remain even when working within clinical practice teams (Braithwaite *et al.*, 2005; Xyrichis and Lowton, 2008; Liberati *et al.*, 2016).

Effective teams work collaboratively, share responsibilities, goals, and decisions, and power is related to expertise rather than traditional hierarchies (Xyrichis and Lowton, 2008; Chan *et al.*, 2010). They also have good communication, and respect for team members, and have an awareness of the roles and expertise of the team members (Dieleman *et al.*, 2004; Atwal and Caldwell, 2006; Jünger *et al.*, 2007). However, American research suggests that other health professionals may not have a full understanding of what dietitians do (Marquis and Gayraud, 2002; Devine *et al.*, 2004). Therefore, the empowerment of dietitians may be facilitated by team members having a better understanding of the roles of dietitians within decision-making for ANH.

8.3.2 Emotional intelligence

Emotional experiences and the response to these experiences were evident in my participants' accounts, and emotional well being and professional practice have been shown to be linked (Rose and Glass, 2006). Appropriate responses to emotions have been identified as forming part of professionalism (Van De Camp *et al.*, 2004) and so form a part of the conceptual framework of professionalism. As previously stated, American dietitians have been encouraged to develop their emotional intelligence (Escott-Stump, 2011; Fox, 2013), and the Dietitians Association of Australia (2015) states that the ability to manage emotions is one of the competencies required for entry into the profession. However, there is no literature about UK dietitians and emotional intelligence.

Some of my participants demonstrated emotional intelligence by being aware of their own emotions, the emotions of others, and by regulating their emotions. The regulation of their own emotions seemed to adhere to display rules to prevent them being disloyal to colleagues, by not showing that they thought patients had received poor care, when they were irritated by patients due to time constraints, when they did not show that they were uncomfortable about long-term ANH in patients they believed to have a poor quality of life, not showing they were sad or upset, and not showing their own religious views. The source for these display rules is not clear and whether or not

these are appropriate display rules could be debated, for example, whether the showing of sadness through crying is appropriate.

There has been some debate and some empirical research about whether crying in a clinical setting is unprofessional. A survey of American medical students and interns reported that 50% of students and 61% of interns cried as the result of a sad clinical situation, and 37% of the respondents believed that it was unprofessional to cry in front of patients (Sung *et al.*, 2009).

However, a survey of American psychologists reported that 72% of therapists cried in front of their patients, with the more experienced therapists being more likely to cry (Blume-Marcovici *et al.*, 2013). An on-line poll of doctors concluded that approximately 62% of those who responded were of the view that it was okay to cry in front of a patient. However, 26% were of the view that it is never acceptable to cry in front of a patient (Gulland, 2014). Bassett and Finlay (2015) suggest that crying is part of a doctor's humanity. The effect this may have on patients is not clear. Some therapists suggest that crying in front of patients may have a therapeutic benefit (Sieger, 2013), while others disagree (Pavan, 2013). The comments associated with the on-line poll reported by Gulland (2014) suggest that a key factor is whether the patient feels uncomfortable or distressed by the doctor's actions. Little is known about what patients think about this; however, one study has surveyed patients who had received treatment for an eating disorder from a therapist who had cried (Tritt *et al.*, 2015). Tritt *et al.* (2015) reported that patients

viewed the crying therapist as a positive thing, as overall they believed that the tears indicated that the therapist understood their experience. Anecdotal evidence does suggest that when health professionals cry it can be comforting for patients (Srivastava, 2015). Therefore, while there is little high quality evidence in this area, it is difficult to make a blanket claim for the display rule that health professionals should not cry, and that it is unprofessional to cry. Therefore, the appropriate display of emotion should be something for professional debate and consensus.

8.3.3 Ethics training

Ethics is integral to the concept of professionalism and professional practice, and seemed to present a challenge to professionalism for some of my participants. For example, some believed that ANH could never be withdrawn and there were challenges related to moral agency, as indicated by P11 when she said, *'I suppose I didn't have the guts to say that [consider withdrawing ANH] to be honest...'* Moral courage, the courage to stand up for ethical principles, is needed for moral agency (Murray, 2010), and ethics training and empowerment contribute to the development of moral courage (LaSala and Bjarnason, 2010). The Health and Care Professions Council's (2013) standards of proficiency for dietitians states that dietitians need to 'understand the ethical and legal implications of withholding and withdrawing feeding...' (Health and Care Professions Council, 2013:7), and if advocacy includes a moral dimension, ethical understanding is required. Having an

understanding of the ethical issues related to ANH may also facilitate communication between team members. So knowledge of the ethical issues related to the provision of ANH is key to professionalism for dietetic practice. While the American Dietetic Association has guidance on ethics specifically for dietitians on ANH (O'Sullivan Maillet *et al.*, 2013; Schwartz, 2015), the British Dietetic Association has not.

8.4 Conclusion to the chapter

This chapter has explained my participants' experiences of involvement in decision-making by relating their experiences to the literature and analysing their experiences through the framework of professionalism. Similar experiences of being involved and not being involved in decision-making have been reported within the nursing and dietetics literature. However, some of the expert roles, the advocate role, and the technician role, have not been identified within dietetics before now.

Positive experiences have been reported within dietetics literature before. However, many of the negative experiences in the accounts of my participants were new and related to their values of trying to provide patient-centred care. These negative experiences appeared to have consequences for my participants, as demonstrated by the emotions they experienced. Accounts of emotional experiences and how dietitians respond to them have not been reported within dietetic practice before. However, the emotional

experiences of moral distress, emotional labour, distancing and desensitisation, moral agency, and the need for support have been reported in other health professionals. The current definitions of emotional labour do not align with the accounts from my participants of hiding their emotions, therefore a broader definition of emotional labour, that is the modification of emotions in order to protect their patients, their colleagues, and themselves, has been suggested.

The recounted experiences suggest that being a dietitian involved in decision-making related to ANH can be professionally challenging. This was an important aspect of my participants' experiences. Even if they were able to influence decisions, they still had emotional challenges related to their practice. There seem to be key challenges related to professionalism that individual dietitians and the profession as a whole need to address. These are the need to raise the status and profile of dietitians, the need to empower dietitians, the need to develop emotional intelligence within dietetics, and the need for ethics training.

In the light of this analysis of the experiences of dietitians, the final chapter will go on to draw conclusions, make an assessment of the originality and contribution to knowledge this thesis has made, and make recommendations for practice, for the British Dietetic Association and for further research.

Chapter 9: Conclusions and recommendations

9.1 Introduction

Malnutrition is a common condition with between 29% and 41% of screened patients admitted to hospital or a care home at risk of malnutrition (Russell and Elia, 2012; Russell and Elia, 2014). Dietitians have a role in identifying patients at risk of malnutrition and in managing those who are malnourished (National Collaborating Centre for Acute Care, 2006; National Institute for Health and Clinical Excellence, 2006). Many people who are malnourished or at risk of malnutrition require artificial nutrition and hydration (ANH) to meet short- or long-term nutritional requirements. Dietitians assess and monitor patients who receive ANH, and as part of the multi-disciplinary team should be involved in decisions about ANH (Andrews, 2004; Armer and White, 2014). Therefore, dietitians are key players in the team involved in caring for patients receiving ANH.

Decisions regarding ANH are often difficult and emotive, and may include end-of-life decisions (O'Sullivan Maillet *et al.*, 2013). Food has a symbolic value and when ANH is withdrawn or withheld it is often viewed as starvation (Whitworth *et al.*, 2004). There is little research about dietitians' involvement in decisions about ANH and what exists has mainly used a survey approach. The use of a qualitative methodology to illuminate dietitians' experiences of their involvement in decision-making related to ANH has not been reported until now.

In this study I have sought to investigate this key aspect of dietitians' work by exploring their experiences of being involved in decisions related to ANH, and by giving voice to their experiences. This is the first UK study to do so, and internationally this is the first qualitative study to examine this phenomenon. Therefore, this study brings new knowledge and understanding of dietitians' lived experiences of involvement in decisions about ANH.

This final chapter briefly summarises this research and draws some conclusions from the study, and then discusses the quality of the research. I will then consider the originality and contribution to knowledge that this thesis makes. Implications for practice, training, the British Dietetic Association, and further research will then follow.

9.2 Summary of research and findings

There is an important gap in the literature regarding dietitians' experiences of decision-making about ANH. The small amount of research conducted with dietitians indicates that dietitians used ethical thinking during decision-making, there were some gaps in some dietitians' knowledge about the benefits of ANH, there were gaps in knowledge of the guidance on withdrawing ANH, and some dietitians believed that they were not adequately involved in the decision-making process. However, much of this research is over ten years old, is non-UK based, and given that healthcare systems may have gone through many reforms, it is likely that dietetic practice may have changed

during that time. Furthermore, this previous research does not give an indication of the everyday lived experiences of dietitians' involvement in decision-making about ANH. Research with nurses had indicated that working with ANH can be emotive, and can lead to feelings of conflict, powerlessness, frustration, and anger, particularly when nurses are not involved in decisions. Until now, little has been known about the emotive nature of dietitians' work within ANH. These gaps in knowledge have contributed to the basis of this research.

This research used an interpretive phenomenological approach to address the research question 'What are dietitians' experiences of being involved in decisions relating to ANH?' The objectives were to explore dietitians' perceptions of their role in decision-making about ANH, and to explore how different contexts influence dietitians' experiences of decision-making about ANH. The nature of the research question and the objectives suggests a qualitative approach would be required, as this would enable behaviours, emotions, and thoughts to be explored. Quantitative research methodologies, for example, surveys, would not allow for in-depth data to be obtained or for the experiences to be fully explored.

Within a qualitative paradigm there are different methodologies which could have been adopted as a mode of enquiry. However, to address the aim and objectives of this research, I needed a methodology which enabled me to

explore the possible multiple realities of experience, as everyone's experience would be different. Those experiences may have been embedded, hidden, or tacit, so I needed a methodology which would reveal the experiences, and allow me to uncover what is normally hidden. Interpretive phenomenology was selected as the most appropriate approach to use, as it aims to interpret, understand, and reveal differences in the human experience. The reflective approach used in interpretive phenomenology enabled hidden experiences to be illuminated. As interpretive phenomenology does not require bracketing of the researcher's experiences, I could use my clinical knowledge as an experienced dietitian to hold the status of an 'insider' in the research. This had several possible advantages, including having a shared identity with the participants, understanding their language and terminology which may have allowed for deeper analysis and reflection during the interviews, and the potential for positive bonding through a shared experience.

However, the lack of bracketing may have been a limitation. As I collected and analysed the data, there was a risk that my preconceived ideas and clinical experience would influence the research process. Therefore, I needed to be aware of this and ensure that I was reflexive throughout the research to minimise the influence of my preconceived ideas.

Within interpretive phenomenology it has been suggested that multiple interviews contribute to the quality of the research, as they enable in-depth reflective interviews (Standing, 2009). I conducted two separate interviews

with 16 dietitians which enabled a reflective exploration of their experiences and also enabled me and my participants to revisit and clarify their experiences. It allowed me to think about their experiences and prepare questions before the second interview. Between the interviews my participants kept a reflective account to develop their reflection of their lived experience. This enabled the focus to be on their experiences rather than hypothetical cases. The first interview may also have helped to develop trust for a deeper exploration of experiences during the second interview. More than 36 hours of interviews were collected, transcribed verbatim by myself, and then analysed using an interpretative phenomenological framework as developed by van Manen (2007).

The findings of this research reveal new important data about dietitians' experiences of decision-making about ANH. The findings make a considerable contribution to, and form new knowledge about, dietitians' work, roles, emotions, and challenges of working within ANH. Three main themes emerged from the data to reveal the lived experiences of dietitians' involvement in decision-making about ANH. 'So much more than just deciding on a feed' revealed that dietitians appeared to undertake the roles of expert, educator, advocate, and technician (the implementation of others decisions): roles which have not been described previously. The theme 'wanting to be heard' revealed that wanting to be involved in decision-making about ANH was central to the lived experience of dietitians. My participants wanted to be

included in decision-making and to have their view respected. Many appreciated that their recommendations may not be adopted, but for them, being heard and respected was key. This study has highlighted that those who were heard during decision-making were known by the team, showed they made a difference to care, and spoke up about patient care, which demonstrated their advocacy role. This study also revealed that the lived experience for some was that of not feeling involved in decisions. When participants were not heard during decisions about ANH, it often resulted in them feeling undermined or disrespected and angry.

The theme 'The emotional roller coaster' illuminated for the first time the mixed emotions that dietitians experienced during their involvement in decisions about ANH and how they responded to them. At times dietitians felt 'proud to do a good job': they had a feeling of pride in their work, they felt respected and valued, and felt that they made a difference to patient care. However, the majority of emotions were negative. Dietitians often described 'feeling angry' when patients were not treated in the way that they believed their patient should be treated, when their views were dismissed, or when they believed that they were not respected as experts. Some felt that 'it's my fault' when feeding did not go to plan or when ANH disrupted discharge plans. Many suggested that they worried about making the correct decisions for other people, and were uncomfortable with naso-gastric tubes being repassed if they had become dislodged. Concerns about long-term ANH for

patients perceived to have a poor quality of life were illuminated in the subtheme 'Is it fair?' A further important finding which has not been reported within dietetics before is that some dietitians experienced 'moral distress', that is, the emotions experienced when dietitians were involved in a treatment that they believed was wrong. This appeared to be experienced when patients who were perceived to have a poor quality of life received ANH, when treatment was deemed inappropriate, or when the dietitians did not have enough information about patients to safely make decisions. The way dietitians responded to the emotions varied. Some hid their emotions, some distanced themselves from the emotional situation, some became desensitised, some spoke out as moral agents, and all of them tried to gain support. Emotional labour is an important concept within my participants' experiences with a broader definition to better illuminate the experience of my participants.

Together, these findings suggest that an important aspect of the lived experience of dietitians' involvement in decision-making was related to their professional identity and the challenges to their professionalism. My participants had a professional identity of being an expert and wanting the best holistic care for their patients. Therefore, when they were not seen as experts, they were unable to advocate for their patients, and when they were used in a technician role and did not agree with the decision, it challenged their professionalism as an expert. These challenges were not only related to

an individual dietitian's clinical practice, but also have wider implications for the profession of dietetics. To address these challenges, the status and profile of dietitians would need to be raised; dietitians may need to be empowered to speak out and show that they are experts enabling them to be more directly involved in decisions. Also, they may need to develop their emotional intelligence in order to cope with difficult situations which will occur when working in the area of ANH, and ethical knowledge may need to be developed in order to support decision-making.

9.3 Quality of research

There is much debate about the standards of inquiry for qualitative research. For this appraisal I have mainly focused on standards of inquiry specifically for interpretive phenomenology. Truthfulness is sometimes considered as a way for rigour to be demonstrated in qualitative research. However, interpretive phenomenology does not aim for one truth as there will be multiple experiences and therefore multiple meanings (de Witt and Ploeg, 2006). Finlay (2011) suggests that the 4Rs: rigour, relevance, resonance, and reflexivity, can help to address the quality of a phenomenological study. Briefly, rigour is related to the conduct of the research. Relevance can be assessed by considering the applicability and contribution to knowledge that the research makes. Resonance addresses whether the research rings true. Reflexivity can be judged through the researcher's account of their position and preconceived ideas which may influence the research process.

Rigour has been demonstrated in this study by a systematic approach being used. There are clear descriptions of processes which were congruent with interpretive phenomenology. My findings have plausibility when considered in the context of the experiences of other health professionals who work with patients receiving ANH, for example, nurses. This research has relevance, as it contributes new knowledge to the experiences of dietitians who work with patients receiving ANH. It also has relevance for dietitians' professional practice, and the findings should influence dietitians' professional practice within the field of ANH. The quotes used to illuminate experiences should allow the reader to 'feel' the powerful experiences the participants shared with me during their interviews which adds to the resonance of the research. When key findings of this research were presented at conferences, they resonated with the experiences of the dietitians who were present.

Armour *et al.* (2009) suggest that the researcher's interpretation of an experience can be a major vulnerability to the quality of interpretive phenomenology, and Morse *et al.* (2002) suggest that the effect of the researcher on the research process 'is the greatest hidden threat to validity' (Morse *et al.*, 2002:18). Therefore, reflexivity is key to address in an appraisal of quality. My pre-assumptions about the research topic will have influenced all stages of the research, from development of the research aim and objectives, the topic guide, the conduct of the interviews, and the interpretation of the data. However, I have been clear about my assumptions

as outlined in section 4.9 on reflexivity, and my supervisors robustly challenged my interpretation of the data. The fact that, as a clinical dietitian, I am in-the-world of dietetics may have illuminated the experiences and aided interpretation. However, I appreciate that my life-world of dietetics will have been different to my participants. I am very aware that it was my interpretation of the participants' experiences, and other people's interpretation of the same data may have been different. My skills as a researcher also need to be considered. Ideally a researcher should be knowledgeable, and flexible and respond to the data during the data collection and data analysis to ensure that they are not simply finding results they were expecting (Morse *et al.*, 2002). I worked hard to position myself as a researcher, not a dietitian, while maintaining my insider status. I also worked hard to use appropriate interviewing skills, such as active listening, paraphrasing, and reflecting. Having not conducted such detailed data analysis before, I learnt about different approaches and the need for clear terminology when discussing the data analysis with my supervisors who guided me through the process.

Sampling is also important for the quality of a study. The sample needs to include people who can provide a rich data set in order to explore the phenomenon of interest. It also needs to be large enough to include a range of experiences from a range of participants, but not so large that too much data will be collected (O'Reilly and Parker, 2013). I used purposive sampling with the inclusion criteria of needing to be a registered dietitian who had

current clinical experience of treating patients requiring ANH, with the aim of recruiting dietitians with a range of experience and grades. One participant was recruited via snowballing. A sample of 16 dietitians was recruited via the West Midlands branch of the British Dietetic Association. The cohort was likely to be adequate to give an authentic view of the experience of decision-making in ANH, as they worked in a range of different clinical settings, had varied years of experience, and resulted in over 36 hours of interview data. A limitation of the sampling was that all the participants were white females who worked in adult services, so male dietitians, dietitians from ethnic groups, and dietitians who work in paediatric services were not represented. Therefore, with hindsight, stratified sampling and snowballing could have been used to try to obtain a broader sample. It must also be noted that the participants recruited for this research were self-selected. They may have volunteered to take part in the study because they had an interest in the topic area, so they are different to those who did not volunteer.

Discussions about the value of member checking in interpretive phenomenology are mixed. Some suggest that it enhances rigour (Armour *et al.*, 2009; Standing, 2009), while others suggest it is not useful in interpretive phenomenology as the researcher interprets all the participants' experiences to a more theoretical level which individual participants may not recognise as their experience (Holloway and Wheeler, 2013). However, within interpretive phenomenology participants should co-interpret their experiences with the

researcher, so including some form of member checking may be of benefit. I used member checking by asking the participants to check the accuracy of their transcripts of their interviews and when the participants' reflective account was discussed with them. Although my participants did not receive the full findings, I have presented some of the findings at conferences, where dietitians were present (Tighe *et al.*, 2013; Tighe *et al.*, 2014a; Tighe *et al.*, 2014b). The informal feedback from dietitians who attended the conferences suggested that my findings did resonate with their experiences.

Triangulation has been defined as using two or more approaches, methods, theories, or researchers to study a single phenomenon (Tobin and Begley, 2004). This is important to consider, as it has been argued that it may increase the quality and quantity of data and so enhance the rigour of a study (Begley, 1996). Method triangulation and data triangulation were included in this research. Method triangulation is when more than one technique is used to collect data, and data triangulation is when a phenomenon is examined from different viewpoints (Kane and O'Reilly-de Brun, 2001). I used two separate in-depth interviews and a reflective account to ensure method triangulation. Data triangulation was obtained by gathering data from different contexts, for example, acute care and community dietitians, and from different levels of experiences, for example, junior and senior dietitians. While there was no researcher triangulation, as data was only collected by myself, I did discuss the data analysis and themes with my supervisors who challenged

my assumptions and the analysis. They also challenged me to justify that the themes were congruent with the data.

With any kind of qualitative research there is the risk of social desirability bias, that is, participants responding in a way they might think that I wanted them to, and/or giving responses that would be expected from a dietitian. In this research, this bias was reduced by using one-to-one interviews rather than focus groups, so there was no peer pressure. Seidman (2006) also suggests that prolonged engagement with participants and an open interviewing style can also reduce social desirability bias, both of which were used in this research.

The methods used in this research were congruent with interpretive phenomenology, as they allowed for reflective data to be collected and interpreted. Observation of practice could have added another dimension to the data, but due to the small number of dietitians working in a given clinical setting this was considered impractical. Overall, the quality of this research has been maintained to produce a credible piece of work.

9.3.1 Limitations

The major limitation was related to the sampling issues, that is, that the participants were self-selected and that no men, ethnic minorities, or paediatric dietitians were included in the research. Also, the views of other

health professionals and patients could have been sought to examine their views on dietitians' involvement in decision-making related to ANH; for example, did patients feel that dietitians did advocate for them? However, for pragmatic reasons, the scope of the research was limited to just dietitians. The generalisability of the research will be considered in the next subsection.

Another limitation was the lack of public engagement in the planning, execution, and feedback of this research. Public engagement with research is encouraged by funding agencies as a way of enhancing public accountability (van Bekkum *et al.*, 2016). Research Councils UK promotes public engagement with research as a way to ensure that research is relevant to society (Research Councils UK, 2014). Including patients in research has the advantage of enabling researchers to gain greater insights and understanding into their research area (Brett *et al.*, 2014a). It can enhance the quality of research and improve its appropriateness (Brett *et al.*, 2014b). It can also have positive effects for patients, who feel valued and empowered (Brett *et al.*, 2014b). As patients will have a different view of the decision-making process compared to dietitians, including patients or carers in the planning of the data collection for this research might have guided the interviews in ways I did not consider.

9.4 Generalisability

Generalisability relates to the extent to which the research findings apply to those in the same setting but who were not sampled, to the wider population,

or to different contexts (Padgett, 2012; Green and Thorogood, 2014). While qualitative research does not aim to have generalisability, it can be useful to consider what Green and Thorogood (2014) refer to as conceptual generalisability. For this research it is how the findings help to make sense of the world of dietitians in order to help understand similar contexts or issues. It is important to consider what the findings might mean for other settings or other populations, so in this case other dietitians who work in ANH and dietitians in general. Within interpretative phenomenology it is not important how many of my participants experienced a phenomenon, after all my participants' lived experiences were different. What is important is that individuals had powerful experiences which have important implications for dietitians' professional practice.

The sample of dietitians recruited for this study were self-selected, did not include men, dietitians from minority ethnic groups, or dietitians who worked in paediatrics, and so caution is needed when applying these findings to other dietitians who work within ANH or to dietitians in general. However, it is likely that dietitians who work in other clinical settings also have a professional identity of an expert and want to do the best for their patient. If this is the case, other dietitians may also experience similar emotions of anger, feeling undermined, or disrespected if they are not viewed as an expert. It is also likely that similar experiences of involvement in decision-making would be experienced in other clinical areas if those decisions were difficult, troubling,

or emotive, for example, in chronic conditions where the dietitian may develop a long-term professional relationship with the patient. Therefore, issues of professionalism may be a factor for dietitians in other areas of clinical practice.

Therefore, while this research may be generalisable to dietitians working in other clinical areas, section 9.6 will mainly focus on implications for practice, training, and the professional association for dietitians working in ANH.

Implications for further research will broaden a little to consider other clinical areas dietitians work in.

9.5 Originality and contribution to knowledge

There has been little qualitative research conducted with dietitians who work in ANH and no research until now has explored the lived experience of dietitians' involvement in decision-making related to ANH. Therefore, this is an original piece of research. I adopted the methodology of interpretive phenomenology, with two interviews and a reflective account, which again has not been used in studies with dietitians before now.

Many of the findings of this research had not been reported within dietetic practice in general or within UK dietetics, so they are a unique and empirical contribution to knowledge. The analysis identified previously unreported roles of UK dietitians who work within ANH. Dietitians actually advocating for patients, and for nutrition and dietetic services, has not been described in the

dietetics literature before now. The role of technician, the implementation of others' decisions, has not been previously described. The attempts of trying to be involved in decisions related to ANH, the ways of being heard and being involved in decisions have not been described from empirical research within dietetics before now. The lack of respect, powerlessness, and lack of influence that some participants described has not been reported within UK dietetic practice before now.

The emotions related to working in the field of ANH have not been described within the dietetic literature until now. Moral distress, emotional labour, distancing, desensitisation, moral agency, and the need for support have also not been previously described. I have suggested that the definition of emotional labour needs to be slightly broader for dietitians, to include the modification of emotions to protect oneself as well as patients and colleagues.

9.6 Implications for practice

Based on the analysis of the data and the emergent themes, the implications for practice which can be drawn from this research are:

1. Dietitians need to be allocated time within their workload to attend ward meetings, case conferences, and multi-disciplinary meetings. This may facilitate the building of relationships, enhance team working, and foster empowerment. My findings suggest that being known, being seen to make a difference to patient care, and showing expertise all

facilitate the dietitian to be heard during decision-making about ANH.

Meetings and ward rounds are an important forum in which to demonstrate these skills and enhance involvement in decision-making.

Working within clinical teams with other healthcare professionals and being physically located with these multi-disciplinary teams (rather than in a dietetic department) may also facilitate this.

2. My data appears to indicate that working within ANH can generate emotional distress and support may be needed. Various models for providing emotional support to healthcare professionals could be considered, including formal supervisions, participation in Schwartz rounds, or more informal support groups. Such support should be structured into dietitians' working patterns. This should help to develop and maintain professional practice and may facilitate empowerment and compassion. When indicated, supervision should include discussion of the ethical dimensions to clinical care in order to improve knowledge of the ethical issues related to ANH and foster moral agency.
3. The findings suggest that both the profile of dietitians and awareness of the need for nutrition support by other healthcare professionals needs to be improved. To raise the profile of dietitians and promote their role, dietitians need to be more proactive in educating others

about nutrition support and their role within it. This should include dietitians' involvement in formal and informal education of medical and nursing students, doctors, and nurses. This may also facilitate the empowerment of dietitians by developing relationships and demonstrating their skills and knowledge.

4. Empowerment of dietitians may facilitate the profession to engage fully with the opportunities afforded by the five-year forward view for the NHS (NHS England *et al.*, 2014), which included plans to use allied health professionals more effectively by developing their roles, and an increased emphasis on patient-led care and the prevention of illness (Imison *et al.*, 2016). The plan includes the development and implementation of new models of care, such as the transfer of care and specialist services from a hospital to a community setting, greater integration of services between primary and acute care, and improvement of services to care homes. To do this, dietitians will need to be proactive in building strong collaborative partnerships with healthcare staff to promote their roles and work together, to be fully involved in decisions, and be viewed as experts in an evolving health service. The findings of this research emphasise that dietitians and the British Dietetic Association need to capitalise on the increased acknowledgment of the importance of allied health professions as part of the new models of care in the NHS.

9.7 Implications for training

The implications for training are linked to the implications for practice, as training may be required for the practice implications to be realised. The implications for pre-registration and post-registration training include:

- 1) To support team working and clinical supervision, training may be required on practice supervision and on the ethical and legal aspects of ANH.

- 2) As well as regular support, dietitians may need training to develop their emotional intelligence to manage the emotional aspects of working within ANH. Such training may include development of reflection skills in order to develop their own self-awareness, social skills, and assertiveness training.

- 3) Emotional labour was evident in the dietitians' accounts, therefore training about emotional labour and the ways to use 'deep acting' as opposed to 'surface acting' when undertaking emotional labour may be of benefit to reduce the risk of emotional dissonance and burnout.

9.8 Implications for the professional association

The findings indicate that some challenges to professionalism may need to be addressed at a professional association level. Therefore, some implications for the British Dietetic Association are as follows:

- 1) There is a lack of UK guidance on the ethical and legal aspects of ANH written for dietitians. Therefore, the British Dietetic Association should develop guidelines regarding the ethical and legal aspects of care related to ANH for UK dietitians. The findings from my research indicate that areas which were particularly troubling for dietitians included long-term ANH in patients perceived to have a poor quality of life and the re-passing of naso-gastric tubes which had been repeatedly dislodged. Therefore, it would be advantageous for the guidance to include these aspects.

- 2) To raise the profile and status of dietitians working within ANH, the British Dietetic Association should produce guidance for doctors on the role of dietitians in nutrition support.

- 3) The lived experience of my participants included the emotional costs of working within ANH. My participants considered that the professional 'display rules' (the informal rules of how to behave) included not showing their emotions. The British Dietetic Association should engage

their members in debate about what are appropriate display rules for a clinical setting.

9.9 Recommendations for future research

This research suggests more areas of research which would further enhance the evidence base of dietetic practice. These might include the following broad topics and questions:

- 1) Generalisability of these findings
 - a. Is the experience of involvement in decisions similar for male dietitians, dietitians from different ethnic groups, paediatric dietitians who work in ANH, and for dietitians who work in other clinical areas?
- 2) Aspects of team working
 - a. How do dietitians interact with the rest of the multi-disciplinary team? Is there a difference in interaction between junior and senior dietitians?
 - b. How do inter-professional relations and healthcare organisational structures influence decision-making about ANH?
 - c. What do other professional groups think about dietitians' involvement in decisions related to ANH?
 - d. What do patients think about dietitians' involvement in decisions related to ANH?

- e. What do UK health professionals perceive the status of dietitians to be?
- f. Would dietitians be empowered by being solely situated within clinical teams or teams of allied health professionals rather than within dietetic departments?

3) Effect of the emotional components of working in ANH

- a. What do dietitians think about showing emotions in front of patients?
- b. Does distancing and desensitisation have an effect on patient care, or the ability to show empathy or compassion?
- c. What is the level of burnout within UK dietitians who work in ANH compared with UK dietitians in general?
- d. How common is emotional labour within dietetic practice for those working in ANH compared to dietetics in general?

4) Dietitians' values

- a. What effect does a dietitian's values or religion have on decision-making?
- b. What effect does a dietitian's values or religion have on their likelihood of experiencing moral distress or emotional difficulties?
- c. What do UK dietitians think about the quality of life of patients receiving long-term ANH in the community? What proportion of

dietitians think that the burden of ANH can outweigh the benefit for some of their patients?

9.10 Final reflections

My participants demonstrated various aspects of professionalism during their discussions of their involvement in decisions about ANH. This was often a challenge. Some participants movingly described their battles to try and do the best for their patients despite the emotional costs to themselves.

Therefore, I will leave the final words to participant P4, senior community dietitian who described this so well:

'We have this saying in our office: "It's like swimming through treacle", and that's how it feels some days, you know. And your arms are tired and you can't be bothered anymore. And some days you do give in to it and just think, "Oh" and, "I can't deal with that today, I really can't put up that fight today"...Sometimes you want to just lie down and give up and not fight any more. But you do, you bounce back, you know, in a couple of days later you think "Right, let's tackle that issue".'

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Appendix 1 – Search strategy

A comprehensive search of the literature was conducted in order to locate articles relevant to my research. For the literature review I wished to locate articles about:

- 1) dietitians and ANH
- 2) ANH and dementia

In order to keep the search as broad and comprehensive as possible, while keeping the search sensitive, AMED - The Allied and Complementary Medicine Database, CINAHL with full text, and MEDLINE were searched using the search strings below and as illustrated in the following screen shots. As a number of databases were searched at the same time, MeSH terms were not used, but free text search terms enabled broad searches. Boolean terms OR and AND were used to combine the search terms.

The search string for ANH was: (Artificial nutrition OR artificial hydration OR intravenous fluid OR tube feeding OR PEG OR nasogastric tube OR percutaneous endoscopic gastrostomy OR hyper alimentation OR clinically assisted nutrition OR enteral feeding OR enteral nutrition OR parenteral nutrition)

The search string for dietitians was (dietitian OR dietician)

The search string for experience was (experience OR beliefs OR attitudes).

The search string for dementia was (dementia OR Alzheimer's disease).

Searches were narrowed by limiting the search terms to the abstract rather than the full text to create a more sensitive search when a large number of hits was obtained. The following screen shots show how the searches were developed to give the find search strategies.

Additional searches were conducted in order to situate my findings within the current literature base as the research progressed and the themes emerged. For example the search string for emotional labour was:

(emotional labour OR emotional labor OR emotion work OR emotional work)

web.b.ebscohost.com/ehost/resultsadvanced?sid=78ad5224-6d1f-4727-93ab-3401e13827a4%0sessionmgr198&vid=5&hid=125&bquery=(TX+(((

Search: AMED - The Allied and Complementary Medicine Database, Show all | Choose Databases

(Artificial nutrition OR artificial hydration OR TX All Text) AND (dietitian OR dietician) TX All Text

Search Results: 1 - 10 of 2,613

1. **Maintaining adequate hydration and nutrition in adult enteral tube feeding.**
 (includes abstract) Dunn, Sasha, British Journal of Community Nursing, 2015; Supplement: S16-23. (journal article - pictorial, review, tables/charts) ISSN: 1462-4753, Database: CINAHL with Full Text
 Subjects: Enteral Nutrition Utilization; Fluid-Electrolyte Balance Evaluation; Malnutrition Prevention and Control; Individualized Medicine; Adult: 19-44 years
 PDF Full Text (1.5 MB)

2. **...cancer centre.**
 (includes abstract) Sheeh, C. H.; Sharp, S.; Walters, E. R.; Journal of Human Nutrition & Dietetics, 2013 Oct; 26 (5): 421-8. (journal article - research, tables/charts) ISSN: 0952-3871 PMID: 23379517, Database: CINAHL with Full Text
 Subjects: Head and Neck Neoplasms Therapy; Enteral Nutrition; Morbidity; Head and Neck Neoplasms Mortality; Treatment Outcomes; Adult: 19-44 years; Middle Aged: 45-64 years; Male; Female
 Show all 9 images
 PDF Full Text (155.8 KB)

3. **Enteral nutrition: an overview.**
 (includes abstract) Holmes, Susan, Nursing Standard, 2012 May 30-Jun 05; 26 (39): 41-46. (journal article - tables/charts) ISSN: 0029-6570 PMID: 22787992, Database: CINAHL with Full Text
 Subjects: Enteral Nutrition; Mainnutrition Therapy
 PDF Full Text (194.4 KB)

4. **Recent developments in enteral feeding for adults: an update.**
 (includes abstract) Medlin, Sophie, British Journal of Nursing, 2012 Oct 11; 21 (18): 1061-7. (journal article - tables/charts) ISSN: 0966-0461 PMID: 23123837, Database: CINAHL with Full Text

Subject: Major Heading

web.b.ebscohost.com/ehost/resultsadvanced?sid=78ad5224-6d1f-4727-93ab-3401e13827a4%0sessionmgr198&vid=7&hid=125&bquery=(AB+(((

Search: AMED - The Allied and Complementary Medicine Database, Show all | Choose Databases

(Artificial nutrition OR artificial hydration OR AB Abstract) AND (dietitian OR dietician) AB Abstract

Search Results: 1 - 10 of 230

1. **Evaluation of delivery of enteral nutrition in mechanically ventilated Malaysian ICU patients.**
 (English) - Abstract available. By: Yip KF, Rai V; Wong KK, BMC Anesthesiology [BMC Anesthesiol], ISSN: 1471-2253, 2014 Dec 23; Vol. 14, pp. 127; Publisher: BioMed Central; PMID: 25587238, Database: MEDLINE
 Subjects: Malaysia; Enteral Nutrition methods; Intensive Care Units; Nutritional Requirements; Respiration, Artificial; Adult: 19-44 years; Aged: 65+ years; Middle Aged: 45-64 years; All Adult: 19+ years; Female; Male
 AB (Artificial nutrition OR artificial hydration OR intravenous fluid OR tube feeding OR PEG OR nasogastric tube OR percutaneous endoscopic gastrostomy OR hyperalimentation OR clinically assisted nutrition OR enteral feeding OR enteral nutrition OR parenteral nutrition) AND AB (dietitian OR dietician)

2. **American Society for Parenteral and Enteral Nutrition and Academy of Nutrition and Dietetics: revised 2014 standards of practice and standards of professional performance for registered dietitian nutritionists (competent, proficient, and expert) in nutrition support.**
 (English) - Abstract available. By: Brantley SL, Russell MK; Mogensen KM; Wooley JA; Bobo E; Chen Y; Malone A; Roberts S; Romano MM; Taylor B, Journal of The Academy of Nutrition and Dietetics [J Acad Nutr Diet], ISSN: 2212-2672, 2014 Dec; Vol. 114 (12), pp. 2001-8.e37; Publisher: Elsevier; PMID: 25443567, Database: MEDLINE
 Subjects: United States; Enteral Nutrition standards; Nutritionists standards; Parenteral Nutrition standards
 Locote! Check for availability

3. **Nonoral feeding for children and youth with developmental or acquired disabilities.**
 (English) - Abstract available. By: Adams RC; Elias ER; Council On Children With Disabilities, Pediatrics [Pediatrics], ISSN: 1098-4275, 2014 Dec; Vol. 134 (6), pp. e1745-62; Publisher: American Academy of Pediatrics; PMID: 25422022, Database: MEDLINE
 Subjects: Child Nutrition Disorders therapy; Developmental Disabilities therapy; Disabled Children; Enteral Nutrition methods; Malnutrition therapy; Child: 6-12 years; All Child: 0-18 years
 Locote! Check for availability

4. **Maintaining adequate hydration and nutrition in adult enteral tube feeding.**
 (includes abstract) Dunn, Sasha, British Journal of Community Nursing, 2015; Supplement: S16-23. (journal article - pictorial, review, tables/charts) ISSN: 1462-4753, Database: CINAHL with Full Text
 Subjects: Enteral Nutrition Utilization; Fluid-Electrolyte Balance Evaluation; Malnutrition Prevention and Control; Individualized Medicine; Adult: 19-44 years

EBSCOhost Searching: AMED - The Allied and Complementary Medicine Database, Show all Choose Databases COVENTRY UNIVERSITY

artificial nutrition OR artificial hydration OR TX All Text Search Clear

AND experience OR beliefs OR attitude TX All Text

AND Select a Field (optional)

Basic Search Advanced Search Search History

Refine Results Search Results: 1 - 10 of 1,862 Relevance Page Options Share

Current Search Find all my search terms: TX (artificial nutrition OR artificial hydration OR intravenous fluid OR tube feeding OR PEG OR nasogastric tube OR naso-gastric tube OR Percutaneous endoscopic gastrostomy OR hyper alimentionation OR clinically assisted nutrition OR enteral feeding OR enteral nutrition OR parenteral nutrition) AND TX (experience OR beliefs OR attitudes)

Limiters Language* English Language* Human* Language* Age Groups* English Language* Human* Age Related* Language* Clear All

Limit To Linked Full Text Abstract Available Image Quick View 1984 Publication Date 2014

1. 'BECAUSE WE SEE THEM NAKED' - NURSES' EXPERIENCES IN CARING FOR HOSPITALIZED PATIENTS WITH DEMENTIA: CONSIDERING ARTIFICIAL NUTRITION OR HYDRATION (ANH).
(Includes abstract) Bryon, Els, Dierckx De Casterle, Bernadette, Gastmans, Chris, Bioethics, 2012 Jul; 26 (6): 285-95. (Journal article - research, tables/charts) ISSN: 0269-9702 PMID: 21320145, Database: CINAHL with Full Text
Subjects: Dementia Therapy, Dementia Complications; Enteral Nutrition Ethical Issues; Inpatients; Parenteral Nutrition Ethical Issues; Decision Making, Clinical Methods; Parenteral Nutrition Adverse Effects; Nurse Attitudes; Adult: 19-44 years; Middle Aged: 45-64 years; Aged: 65+ years; Male; Female
Academic Journal PDF Full Text (254.4KB)

2. Alterations in fluid, electrolytes and other serum chemistry values and their relations with enteral tube feeding in acute brain infarction patients.
(Includes abstract) Oh H; Seo W; Journal of Clinical Nursing, 2007 Feb; 16 (2): 298-307. (Journal article - research, tables/charts) ISSN: 0962-1067 PMID: 17239065, Database: CINAHL with Full Text
Subjects: Stroke Complications; Stroke Therapy; Enteral Nutrition Adverse Effects; Fluid-Electrolyte Balance; Fluid-Electrolyte Imbalance; Fluid-Electrolyte Imbalance Etiology; Aged: 65+ years; Female; Male
Academic Journal PDF Full Text (521.5KB)

3. Struggling in an inescapable life situation: being a close relative of a person dependent on home enteral tube feeding.
(Includes abstract) Bjuresäter, Kaisa; Larsson, Maria; Athlin, Etsy; Journal of Clinical Nursing, 2012 Apr; 21 (78): 1051-9. (Journal article - research, tables/charts) ISSN: 0962-1067 PMID: 21418362, Database: CINAHL with Full Text
Subjects: Home Nutritional Support; Enteral Nutrition; Family Psychosocial Factors; Adult: 19-44 years; Middle Aged: 45-64 years; Aged: 65+ years; Aged, 80 and over; Male; Female
Academic Journal

EBSCOhost Searching: AMED - The Allied and Complementary Medicine Database, Show all Choose Databases COVENTRY UNIVERSITY

artificial nutrition OR artificial hydration OR AB Abstract Search Clear

AND experience OR beliefs OR attitude AB Abstract

AND Select a Field (optional)

Basic Search Advanced Search Search History

Refine Results Search Results: 41 - 50 of 117 Relevance Page Options Share

Current Search Find all my search terms: AB (artificial nutrition OR artificial hydration OR intravenous fluid OR tube feeding OR PEG OR nasogastric tube OR naso-gastric tube OR Percutaneous endoscopic gastrostomy OR hyper alimentionation OR clinically assisted nutrition OR enteral feeding OR enteral nutrition OR parenteral nutrition) AND AB (experience OR beliefs OR attitudes)

Limiters Language* English Language* Human* Language* Age Groups* English Language* Human* Age Related* Language* Clear All

Limit To Linked Full Text Abstract Available Image Quick View 1993 Publication Date 2014

41. Prevailing ethical dilemmas in terminal care for patients with cancer in Taiwan.
(Includes abstract) Chiu TY; Hu WY; Huang HL; Yao CA; Chen CY; Journal of Clinical Oncology, 2009 Aug 20; 27 (24): 3964-8. (Journal article - research) ISSN: 0732-183X PMID: 19470919, Database: CINAHL with Full Text
Subjects: Neoplasms Therapy; Terminal Care Ethical Issues; Adult: 19-44 years; Female; Male
Academic Journal Locate Check for availability

43. Hypervitaminosis A in pediatric hematopoietic stem cell patients requiring renal replacement therapy [corrected] [published erratum appears in NUTR CLIN PRACT 2009 Feb-Mar;24(1):109].
(Includes abstract) Lipkin AC; Lenssen P; Nutrition in Clinical Practice, 2008 Dec-2009 Jan; 23 (6): 621-9. (Journal article - research, tables/charts) ISSN: 0884-5336 PMID: 19033221, Database: CINAHL with Full Text
Subjects: Hematopoietic Stem Cell Transplantation in Infancy and Childhood; Hypervitaminosis A Etiology; Kidney Failure, Chronic Complications; Parenteral Nutrition in Infancy and Childhood; Renal Replacement Therapy Methods; Adolescent: 13-18 years; Adult: 19-44 years; Child: 6-12 years; Child, Preschool: 2-5 years; Infant: 1-23 months; Female; Male
Academic Journal Show all 5 images PDF Full Text (50.7KB) Locate Check for availability

44. Decision-making for gastrostomy and ventilatory support for people with motor neurone disease: variations across UK hospices.

EBSCOhost

Searching: AMED - The Allied and Complementary Medicine Database, Show all Choose Databases

artificial nutrition OR artificial hydration OR AB Abstract Search Clear

AND experience OR beliefs OR attitude AB Abstract

AND decision making OR decision-making Select a Field (optional)

Basic Search Advanced Search Search History

Refine Results

Search Results: 1 - 10 of 17

Relevance Page Options Share

1. Attitudes regarding life-sustaining measures in people born in Japan, China, and Vietnam and living in Texas.

(includes abstract) Duke, Gloria; International Journal of Palliative Nursing, 2013 Feb; 19 (2): 76-83. (journal article - research, tables/charts) ISSN: 1357-6321 PMID: 23436536, Database: CINAHL with Full Text

Subjects: Life Support Care; Attitude to Health; Terminal Care; Cultural Values; Decision Making; Patient; Decision Making; Family; Adult: 19-44 years; Middle Aged: 45-64 years; Aged: 65+ years; Aged: 80 and over; Male; Female

2. BECAUSE WE SEE THEM NAKED - NURSES' EXPERIENCES IN CARING FOR HOSPITALIZED PATIENTS WITH DEMENTIA: CONSIDERING ARTIFICIAL NUTRITION OR HYDRATION (ANH).

(includes abstract) Bryon, Els; Dierckx De Casterlé, Bernadette; Gastmans, Chris; Bioethics, 2012 Jul; 26 (6): 285-95. (journal article - research, tables/charts) ISSN: 0269-9702 PMID: 21320145, Database: CINAHL with Full Text

Subjects: Dementia Therapy; Dementia Complications; Enteral Nutrition Ethical Issues; Inpatients; Parenteral Nutrition Ethical Issues; Decision Making; Clinical Methods; Parenteral Nutrition Adverse Effects; Nurse Attitudes; Adult: 19-44 years; Middle Aged: 45-64 years; Aged: 65+ years; Male; Female

3. The bioethical experiences of student dietitians on their final clinical placement.

(includes abstract) Tighe, B.; Mainwaring, J.; Journal of Human Nutrition & Dietetics, 2013 Apr; 26 (2): 198-203. (journal article - research, tables/charts) ISSN: 0952-3871 PMID: 23190344, Database: CINAHL with Full Text

Subjects: Students; Dietetics; Dietetics Ethical Issues; Ethics; Professional; Student Attitudes; Adult: 19-44 years

Limit To

Linked Full Text

Abstract Available

Image Quick View

1997 Publication Date 2014

web.b.ebscohost.com/ehost/breadbox/search?term=AB (artificial nutrition OR artificial hydration OR intravenous fluid OR tube feeding OR PEG OR nasogastric tube OR naso-gastric tube OR Percutaneous endoscopic gastrostomy OR hy...

EBSCOhost

Searching: AMED - The Allied and Complementary Medicine Database, CINAHL with Full Text, MEDLINE Show Less Choose Databases

artificial nutrition OR artificial hydration OR AB Abstract Search Clear

AND decision making AB Abstract

AND dementia OR Alzheimer's Disease AB Abstract

Basic Search Advanced Search Search History

Refine Results

Search Results: 1 - 10 of 15

Relevance Page Options Share

1. Nurse-physician communication concerning artificial nutrition or hydration (ANH) in patients with dementia: a qualitative study.

(includes abstract) Bryon, Els; Gastmans, Chris; de Casterlé, Bernadette; Dierckx, Roger; Journal of Clinical Nursing, 2012 Oct; 21 (19/20): 2975-84. (journal article - research, tables/charts) ISSN: 0962-1067 PMID: 22642618, Database: CINAHL with Full Text

Subjects: Nurse-Physician Relations; Communication; Dementia Diet Therapy; Geriatric Nutrition; Decision Making; Clinical; Fluid Therapy In Old Age; Adult: 19-44 years; Middle Aged: 45-64 years; Aged: 65+ years; Male; Female

2. A survey of the reasons patients do not chose percutaneous endoscopic gastrostomy/jejunostomy (peg/pej) as a route for long-term feeding.

(includes abstract) Lin, Li-Chan; Li, Mei-Hui; Watson, Roger; Journal of Clinical Nursing, 2011 Mar; 20 (5/6): 802-10. (journal article - research, tables/charts) ISSN: 0962-1067 PMID: 21320205, Database: CINAHL with Full Text

Subjects: Gastrojejunostomy Tubes Utilization; Treatment Refusal; Decision Making; Patient; Enteral Nutrition Methods; Infant: 1-23 months; Child, Preschool: 2-5 years; Child: 6-12 years; Adolescent: 13-18 years; Adult: 19-44 years; Middle Aged: 45-64 years; Aged: 65+ years; Aged: 80 and over

3. Prevalence and in-hospital mortality of gastrostomy and jejunostomy in Japan: a retrospective study with a national administrative database.

(includes abstract) Sako, Akahito; Yasunaga, Hideo; Horiguchi, Hiromasa; Fushimi, Kiyohide; Yanai, Hidekatsu; Uemura, Naomi; Gastrointestinal Endoscopy, 2014 Jul; 80 (1): 88-96. (journal article - research, tables/charts) ISSN: 0016-5107 PMID: 24472760, Database: CINAHL with Full Text

Subjects: Gastrostomy Tubes Utilization; Jejunostomy Tubes Utilization; Prevalence; Middle Aged: 45-64 years; Aged: 65+ years; Aged: 80 and over; Male.

Limit To

Linked Full Text

Abstract Available

Image Quick View

2000 Publication Date 2014

web.b.ebscohost.com/ehost/breadbox/search?term=AB (artificial nutrition OR artificial hydration OR intravenous fluid OR tube feeding OR PEG OR nasogastric tube OR naso-gastric tube OR Percutaneous endoscopic gastrostomy OR hy...



Searching: Academic Search Complete, Show all Choose Databases

COVENTRY UNIVERSITY

decision making OR decision-making Select a Field (optional) Search Clear

AND Artificial nutrition OR artificial hyd Select a Field (optional)

AND experience OR beliefs OR attitud Select a Field (optional) + -

Basic Search Advanced Search Search History

Search History/Alerts

Print Search History Retrieve Searches Retrieve Alerts Save Searches / Alerts

<input type="checkbox"/> Select / deselect all		Search with AND	Search with OR	Delete Searches	Refresh Search Results
Search ID#	Search Terms	Search Options	Actions		
<input type="checkbox"/> S10	(decision making OR decision-making) AND (Artificial nutrition OR artificial hydration OR intravenous fluid OR tube feeding OR PEG OR nasogastric tube OR percutaneous endoscopic gastrostomy OR hyper alimentation OR clinically assisted nutrition OR enteral feeding OR enteral nutrition OR parenteral nutrition) AND (experience OR beliefs OR attitudes)	Search modes - Find all my search terms	View Results (397) View Details Edit		

Appendix 2 – Topic guide

NB: Text in bold as questions, remainder as prompts and probes for the interviewer

Introduction

Can you tell me about yourself?

- Age
- Ethnic group
- Religion
- Qualifications and when graduated.

Can you tell me about the area of dietetics you work in?

- Clinical area
 - Who do you work with?
- Primary/secondary care
- Years of experience
 - Previous clinical experience and work areas

Clinical practice

Can you tell me about a straight forward recent case which related to ANH. I want to talk about the experience of this, e.g. the background rather than the clinical detail such as which feed to use or calculation of requirements.

- **Please could you describe the situation for me.**
 - Contextual features -
 - clinical information about the patient
 - ? able to give consent
 - type of ward/situation
 - specialist team?
 - Who else was involved in this case? (family, MDT).
- **What pieces of information did you use when making decisions about this case?**
 - Probe about ethical considerations, e.g. was the patient involved in the decision-making process? Did everyone agree with the decision made? Was it relevant to think about best interest or futile care?
- **What made this a straight forward case?**
- **What was it like for you to be involved in this case?**
- **How did you feel about this experience?**
 - Probe to find out why they felt in the way described

Can you think about a time when you were in a difficult situation with regard to providing ANH. I would like you to talk about the experience of this, i.e. the background etc, rather than the clinical detail, e.g. I wasn't sure which feed to use.

- **Please could you describe the situation for me.**
 - Contextual features -
 - clinical information about the patient
 - ? able to consent
 - type of ward/situation
 - specialist team?
 - Who else was involved in this case? (family, MDT).
- **What pieces of information did you use when making decisions about this case?**
 - Probe about ethical considerations, e.g. was the patient involved in the decision-making process? Did everyone agree with the decision made? Was it relevant to think about best interest or futile care?
- **What happened to make this a difficult case?** (if not already clear)
- **What was it like for you to be involved in this case?**
- **How did you feel about this?**
- **What would have made it easier for you?**
- **Why would this have made it easier for you?**
- **Did you talk to anyone about this situation? If so who?**
- **Was it helpful to talk to this person/people? How was it helpful?**
- **If you had to give this a number out of ten for difficulty what would it be?**
- **Can you describe a 10 out of 10 situation**
- **You have described a real situation, there is any guidance you are aware of which can help with making these types of situations?**

Appendix 3 – Reflective account

A reflective account of a clinical event related to ANH for the second interview

Please could you reflect on an event related to providing ANH you have been involved with this week. Please use the following questions to help with this rather than using a reflective cycle. Please do not disclose any sensitive information which could identify the patient/client in this reflection.

What is the background to the situation?

What do you think are the important issues for this case and the decision-making process in this case?

How did you feel about the situation?

Why did you feel like this?

Did you talk to anyone about this situation? If so who?

Was it helpful to talk to this person/people? If so, why was it helpful?

Could this situation have been made easier for you? If so how?

Why would this have made it easier for you?

Appendix 4 – Field notes form

Observational notes

Interview with

Location.....

How did the participant appear?

Comments on NVC

Theoretical notes

What do I think is going 'on' after this interview?

Methodological notes

Issues for me to take into account for the next interview

Personal notes

How did I feel the interview went?

Appendix 5 – Email to West Midlands branch of the British Dietetic Association

The experience of dietitians involved in providing non-oral nutrition

Dear Dietitian

The West Midlands Branch of the BDA has kindly allowed me to contact you to invite you to take part in a research project.

Are you a dietitian that has artificial nutrition and hydration as part of your case load?

Would you be happy to talk about your experience of these situations?

If the answer is yes, then please read on! If the answer is no, please consider forwarding this email to someone who does.

The research project is exploring dietitians' experience of ethical challenges in artificial feeding. Ethical approval has been obtained from the Local Research Ethics Committee. Taking part in the research would mean giving up some time to be interviewed, completing one reflective account of a clinical event related to providing artificial nutrition and hydration (which could be used for your CPD) and then be interviewed again.

If you would like to receive more information about this research please complete the information below and email it back to Bernice Tighe, it will take less than a minute to do! Just copy and paste the following information and then click the link below to email Bernice.

Name

Telephone number

Main area of clinical work

Main location e.g. hospital, community

How many years of clinical experience?

Current position (Band)

[Please click here](#)

Many thanks

Bernice Tighe

Appendix 6 – Participant Information sheet

Dietitians' experience of ethical challenges in artificial feeding.

Thank you for reading this information sheet carefully.

You are being invited to take part in a research project which will explore the experience of dietitians who are involved in situations related to providing artificial nutrition and hydration (ANH).

Before you decide whether or not to take part in this project, it is important for you to understand why the project is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Please also take your time to decide whether or not you wish to take part.

What is the purpose of this project? The aim is to explore the experience of dietitians who are involved in ethical situations related to providing artificial nutrition and hydration.

Why have I been chosen? You have been chosen because you are a dietitian who has experience of providing artificial nutrition and hydration in clinical situations.

Do I have to take part? It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and will be asked to sign a consent form. You can withdraw your participation at any time.

What will happen to me if I take part? You will be asked to take part in two interviews which will be recorded. It is expected that each interview will last about 60-90 minutes. During the interviews you will be asked about clinical situations related to providing nutrition and hydration. Your words and views may be quoted in the project report, but no information can be traced back to you personally. You will be asked to keep a reflective account of one clinical event related to providing artificial nutrition and hydration between the first and second interview. You will be asked to email this to the researcher. This will then be used as a basis to re-interview you.

What are the possible disadvantages and risks of taking part? There are no physical risks to taking part, but you will be asked to provide your time and keep a reflective account. There is a small risk that you may become distressed by talking about difficult clinical situations. If this happens you will be offered the opportunity to pause or end the interview and be encouraged to contact the British Dietetic Association for advice. As the research is being

undertaken by a registered dietitian, the researcher has a duty to report any serious breaches of the Health Professions Council's code of conduct which would seriously affect patient care. Please note that the researcher is not checking or judging your practice and only seriously unsafe practice would be reported.

What are the possible benefits of taking part? All dietitians (not just the participants) should benefit from the research in that a general understanding of the experience of dietitians related to these ethical situations will have been explored. The reflective account you complete can make up part of your CPD portfolio.

What if something goes wrong? It is very unlikely that something will go wrong during the course of this project. However, if you have any concerns or questions about any aspect of this project, you should contact the lead researcher who will do their best to answer your questions (i.e., Bernice Tighe, contact details below).

If you remain unhappy and wish to complain formally, you can do this through Dr Peter Hedges, Director, Research Support Services, University of Warwick, University House, Kirby Corner Road, Coventry, CV4 8UW Tel: 024 7652 3716. Email: P.A.Hedges@Warwick.ac.uk

Warwick University has in force a Public and Products Liability policy which provides cover for claims for "negligent harm" and the activities here are included within that coverage subject to the terms, conditions and exceptions of the policy. Any complaints you may have about the conduct of the project should be taken up with Coventry University (i.e., Dr Peter Hedges, contact details as below).

Will my taking part in this project be kept confidential? All information which is collected from you during the course of the project will be kept strictly confidential and processed in accordance with the Data Protection Act 1998. All information will be anonymised, and access to the information will be restricted to lead researcher. Recordings of the interviews will be erased immediately after transcription.

What will happen to the findings of the project? The findings of the research will be written up for publication in a scientific journal and will contribute to a PhD thesis. The findings of this project will be presented at the West Midlands Branch of the British Dietetic Associations branch meeting and may be presented at conferences. You will not be identified in any report or publication.

Who is organising the project? The project is sponsored by the Warwick University and is part of PhD studies for Bernice Tighe. Ethical approval has been obtained from the Local Research Ethics Committee. If you require

additional information contact the lead researcher Bernice Tighe (024 7688 8719 or b.tighe@coventry.ac.uk)

Who do I contact for further information or advice? If you need any more information about the project, please contact the lead researcher (i.e., Bernice Tighe contact details below).

Contact details.

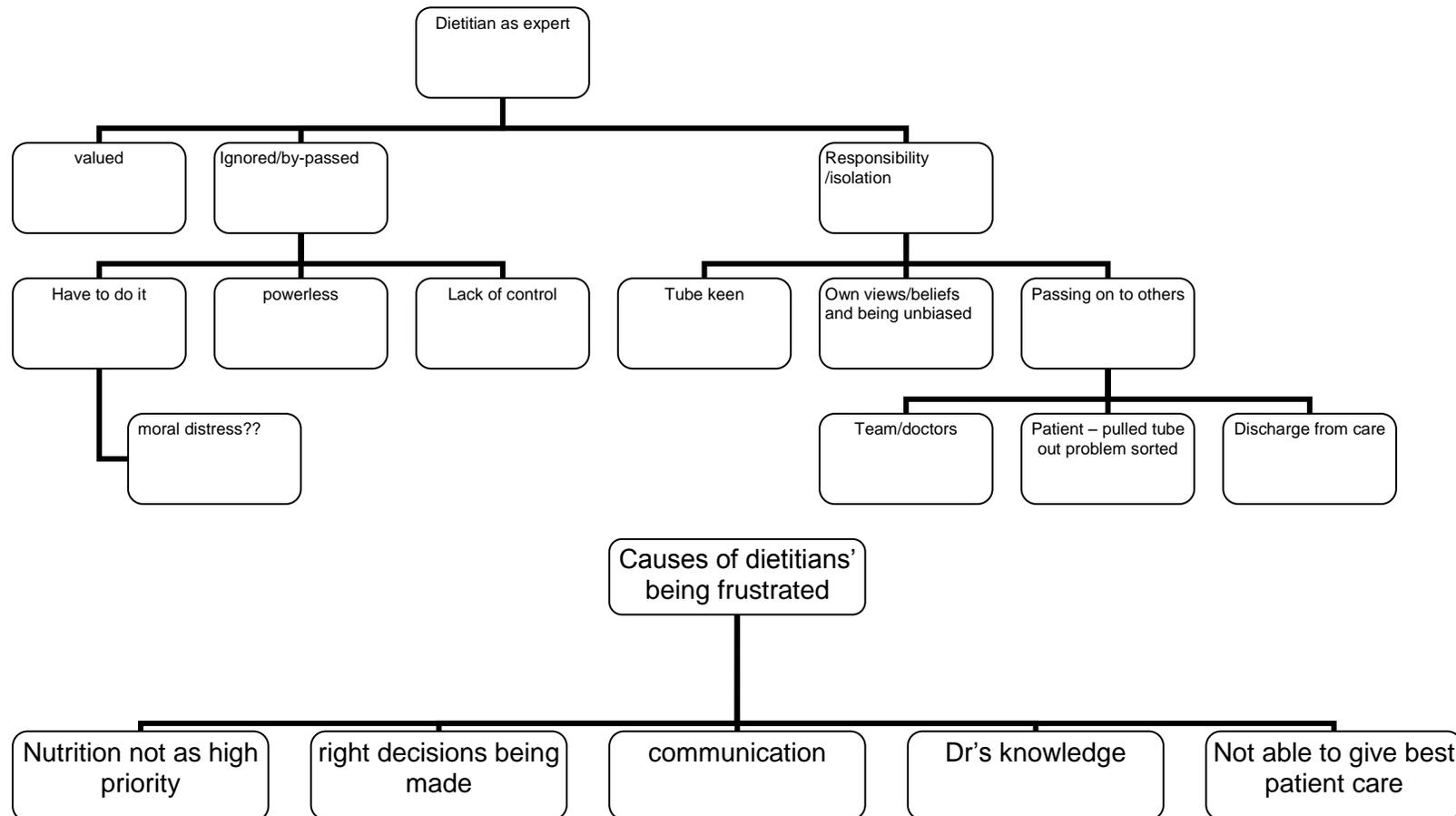
Lead Researcher: Bernice Tighe, senior lecturer, CW216, Coventry University, Priory Street, Coventry University, CV1 5FB. Tel: 024 7688 8719. Email: b.tighe@coventry.ac.uk

Warwick University: Dr Peter Hedges, Director, Research Support Services, University of Warwick, University House, Kirby Corner Road, Coventry, CV4 8UW, Tel: 024 7652 3716 Email: P.A.Hedges@Warwick.ac.uk

Thank you for your time.

Appendix 7 – Development of themes

The follow diagrams, tables and screen shots illustrate how the themes emerged from the data



NVivo categories

The screenshot displays the NVivo software interface. The top menu bar includes File, Home, Create, External Data, Analyze, Explore, Layout, and View. The left sidebar shows a tree view of nodes, with 'Tree nodes' selected. The main window displays a table of tree nodes and their source counts.

Name	Sources
managed feelings	0
Feeling weight on shoulders	6
Dignity	9
Are they telling us something	9
Role of food and nutrition in caring	16
Is it right	14
Burdens	6
Support	16
Feeling comfortable with the situation	14
Emotional labour	16
Feeling uncomfortable with the situation	16
control	0
Battles	7
Conflict	12
Feeling in control of the decision or situation	10
Powerlessness and lack of control	14
Patient information giving	15
Respect	14
Involvement in the decision making process	15
Frustrations	15
Dietitian as expert	0
Honesty and truth telling	10
Responsibility	13
Benefit vs burden to inform decision	10
Moral agency	8
Moral distress or moral outrage	14
Expert	13
Other HCP views	15
the wider team, patient and working issues	0
Religion in decision making	7
Expectations	12
Policy and procedure	12
Team working	15
Relationships	16
Communication	15

The wider team including the patient and working issues									
Religion in decision-making	Team working	Relationships	Communication	Expectations	Policy and procedure				
Dietitian as expert									
Moral agency	Expert	Other HCP views	Moral distress or moral outrage	Benefit vs burden to inform decision	Honesty and truth telling	Responsibility			
Managed feelings									
Is it right	Support	Dignity	Feeling weight on shoulders	Feeling uncomfortable with the situation	Emotional labour	Burdens	Feeling comfortable with the situation	Role of food and nutrition in caring	Are they telling us something
Control									
Involvement in the decision-making process	Frustrations	Battles	Respect	Powerlessness and lack of control	Patient information giving	Conflict	Feeling in control of the decision or situation		

The varied roles of dietitians in decision-making											
Dietitian as an Expert	Dietitian as Decision Maker	The Dietitian as Technician	Tactician	Dietitian as an Information Giver	Dietitian as a PEG Counsellor	The Dietitian as an Information Gatherer	The Dietitian as an Advocate	Educator	Pragmatist		
Who has the power in decision-making related to ANH?											
Dietitians and power				Dietitians experience of powerlessness							
Power as the expert	Power with patients	Power to challenge and speak up and be an advocate		Powerlessness and the technician role	Powerlessness in the presence of Doctors - the 'white coat' effect	Clinical situations and powerlessness	Organisational influences on powerlessness	Organisation advocacy			
Dietitians and moral agency											
Enablers of moral agency						Inhibitors of moral agency					
Being expert	Awareness of moral standards	Professional integrity	Moral courage	Ability to influence change	Taking responsibility for actions	reflecting on actions	Support	Lack of influence on decisions	Other views of HCP/hierarchy within teams	Lack of confidence for moral agency	Lack of moral courage or taking responsibility
Managing emotions in decision-making											
Don't show it		Keeping a distance		Becoming desensitised		Moral agency		You have to have some support			

Appendix 8 – Consent form

Title of Project: Dietitians' experience of ethical challenges in artificial feeding

Name of Chief Investigator: Bernice Tighe, Senior lecturer, Coventry University, Priory Street, Coventry, CV1 5FB. 024 7688 8719

Sponsor: Warwick University.

Please initial box

1. I confirm that I have read and understand the information sheet dated 30/6/10 for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, *or without affect my legal rights.*
3. I agree that any words I say in an interview with the researcher can be recorded, and may be used, anonymised, in the presentation of the research. *These words will not be identified to me.*
4. I agree that the words I write in a reflective account may be used, anonymised, in the presentation of the research. *These words will not be identified to me.*
5. I agree to take part in the above study.

Name of Participant

Signature

Date

Name of Witness/ Researcher

Signature

Date

Copy to participant
Copy for research records

Appendix 9 – Ethical approval

Before this research was conducted, ethical approval was obtained from the National Research Ethics Service Committee West Midlands - Coventry and Warwickshire.



Coventry & Warwickshire Research Ethics Committee

Prospect House
Fishing Line Road
Enfield
Redditch
B97 6EW

Telephone: 01527 582535
Facsimile: 01527 582535

13 July 2010

Ms Bernice Tighe
Senior lecturer
Coventry University
CW216, Coventry University
Priory Street
Coventry
CV1 5FB

Dear Ms Tighe

Study Title: Dietitians' experience of ethical challenges in artificial feeding
REC reference number: 10/H1211/13

The Research Ethics Committee reviewed the above application at the meeting held on 30 June 2010. Thank you for attending to discuss the study.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Although not a condition of approval the committee would like you to consider having another appropriate person available to support participants in case of distress.

If you wish to speak to a member of the committee about this decision then you would be able to speak to the Chair (via the Coordinator).

Further Ethical Issues Discussed

You will be telling the participants at consent that confidentiality could be broken if there was a serious breach of the code of conduct. How will level of risk be decided?

It would be something that could cause serious patient harm. We are not going into clinical issues to any depth so it is unlikely that there would be a serious disclosure. The only risk in the dietitian's responsibility is dehydration. The dietitians are not in charge of overall patient care.

The reflective exercise could involve other disciplines. Could there be disclosure of actions of other disciplines.

In that case the code of conduct would be followed.

In the case of a participant experiencing distress they would need more immediate support than to contact the British Dietetic Association.

This could be arranged. We are used to handling distressing situations.

The reflective exercise is to take 20 minutes. Is this long enough?

Prompt questions are to be used.

Will the recordings be kept?

They will be destroyed once transcribed.

What is the effect of the participants being known to the researcher?

It will be an equal relationship in the research situation.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>. Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Investigator CV	1	01 May 2010
Protocol	3	01 May 2010
Supervisors CV	1	01 May 2010

REC application		20 May 2010
Covering Letter		01 June 2010
Interview Schedules/Topic Guides	1	01 May 2010
Advertisement	2	01 May 2010
Letter of invitation to participant	1	01 May 2010
Participant Information Sheet	3	01 May 2010
Participant Consent Form	2	01 May 2010
Evidence of insurance or indemnity		17 July 2009
Referees or other scientific critique report		16 March 2010

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

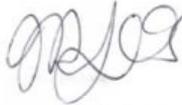
We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H1211/13

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely



Reverend Mark Bratton
Acting Chair

Email: jenny.tyers@westmidlands.nhs.uk

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments
"After ethical review – guidance for researchers"

Copy to: Dr Peter Hedges,
University of Warwick
University House, Kirby Corner Road
Coventry, CV4 8UW



National Research Ethics Service
NRES Committee West Midlands - Coventry & Warwickshire

Prospect House
Fishing Line Road
Enfield
Redditch
B97 6EW
Tel: 01527 582532
Fax: 01527 582540

Date: 05 July 2011

Ms Bernice Tighe
Senior lecturer
Coventry University
CW216, Coventry University
Priory Street
Coventry
CV1 5FB

Dear Ms Tighe

Study title: Dietitians' experience of ethical challenges in artificial feeding
REC reference: 10/H1211/13

Thank you for sending the progress report for the above study dated 30 June 2011. The report will be reviewed by the Chair of the Research Ethics Committee, and I will let you know if any further information is requested.

The favourable ethical opinion for the study continues to apply for the duration of the research.

As requested, I have disabled the Annual Report reminders.

10/H1211/13:	Please quote this number on all correspondence
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Yours sincerely

Mrs Rosa Downing
Committee Co-ordinator

E-mail: Rosa.Downing@westmidlands.nhs.uk

Copy to: Dr Peter Hedges,

Appendix 10 – Excerpts from my reflexivity diary

Some excerpt from my reflective diary made during the data collection stage.

I'm trying hard to be a researcher rather than a dietitian and not give people the answer or tell them what to do when they talk about clinical situations. Also trying not to guide them too much. However, it is important for them to know that I am a dietitian, and that I understand what they are talking about. I mustn't lose the insider status, my relationship with them is important for them to feel safe and to open up to me. But it needs to be balanced by being an objective researcher. However, I do feel that getting them to talk about their experiences and reflecting on it needs to happen before they can make sense of it and will help them to come up with some of the answers.

Also trying not to show how surprised and shocked I am by some of the answers some have given and trying not to be impressed with others; some are really holistic. I am trying to be mindful about how I act, as I do not want it to appear as if I'm judging them. I needed to be aware of my thoughts and feelings and make sure I don't show them, especially when I would not have done what some dietitians have done. Remember everyone's practice is different! And in order to get people to open up and be honest, I must not be judgemental.

I have felt irritated by the participant I interviewed today. I wanted answers to my questions and she was quite politician-like in the way she side-stepped questions. This just seemed to be about the emotional aspects of her experience. "How did you feel?" got very little back. I wonder why this was? Maybe she is just a private person when it comes to feelings. The interviews are a two way street, so I must work hard not to show my irritation. All I can do is try to create an interview environment which is open and supportive, non-judgemental and facilitate their thinking about their experiences. I need to be okay with the fact that some people just won't want to open up to me. After all they all giving up their time for me! Most people have been very open, so I'm hoping it's not me. Is there anything about that interview which was different? I wonder how I would be if I was being interviewed?

I'm finding some interviews easier and more enjoyable than others. Maybe some people are just more articulate and open, maybe I just like some people more than others on a human personal level and as clinicians. I can't help that, but I do need to try to get everyone to open up if possible, (although some personalities will be more reserved I guess).