An Exploration of early Palliative Care in Adult Patients with Cystic Fibrosis and Healthcare Professionals.

by

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Thesis
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Faculty of Health and Medical Sciences School of Health Sciences

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Statement of Originality

This thesis and the work to which it refers are the results of my own efforts. Any ideas, data, images or text resulting from the work of others (whether published or unpublished) are fully identified as such within the work and attributed to their originator in the bibliography or in footnotes. This thesis has not been submitted in whole or in part for any other academic degree or professional qualification.

Name: Anna-Marie Stevens

Signature:

[Signature]

Date: 12th December 2014
An Exploration of early Palliative Care in Patients with Cystic Fibrosis and Health Care Professionals

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Abstract

Background:
Cystic Fibrosis (CF) is one of the United Kingdom’s most common life limiting genetic disorders. Improvement in treatment modalities over the last 20 years has resulted in this group of patients living longer. The acceptability of accessing early palliative care for patients with CF and staff perceptions of a palliative care referral for this group is relatively unexplored. Integrated care has been used as a theoretical model to underpin this study.

Aim:
To explore the experience and perceptions of patients with CF and staff regarding palliative care and the acceptability of this as a service early in the patient’s disease trajectory.

Method:
A Mixed Methods Study informed this research. This three phase study included a Focus Group (phase 1) with 8 experts from both CF and palliative care, a national survey (phase 2) with 46 experts from CF and palliative care teams, and 17 interviews (phase 3) with patients with CF and health care professionals who care for patients with CF.

Results:
The term “palliative care” remains a barrier for some professionals in considering a referral to palliative care. Patients interviewed did not have such a problem with the term. Patients are supportive of palliative care being introduced earlier in the disease trajectory. Currently there is evidence to suggest that over 50% of teams do not have an integrated service between CF and palliative care.

Discussion:
This innovative study has identified a lack of clarity relating to when a patient with CF should be referred to palliative care services. Uncontrolled symptoms and transplant have been highlighted as potential triggers for referral to palliative care services. Patients have recognised that transplant may be too late for a referral and would like to be made aware of palliative care services earlier in the disease pathway. A model of integrated care has been generated from the findings of the study.

Conclusion
This study has explored early palliative care in adults with CF and considered the perceptions and experiences of patients and health care professionals. This three phase study has determined the views of patients for the first time regarding early palliative care. Together with national data in phase two and in depth interviews in phase three, an integrated model between CF and palliative care is proposed that illustrates the views of the patients and health care professionals, offering considerations for organisations in the development of integrated services.

Key words: Cystic Fibrosis, Palliative Care, Integrated Care, patient and health care professional perceptions and experiences.
Acknowledgements

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CHAPTER 1: INTRODUCTION TO THE THESIS

1.1. Introduction

This study explores the experiences and perceptions of patients with Cystic Fibrosis and of health care professionals regarding palliative care and the acceptability of this service early in patients’ disease trajectories. The chapters of this thesis are structured from 1 to 8. The following presents a guide for the reader. Chapter 1 introduces palliative care, non-malignant disease and explores the theoretical model of integrated care. Chapter 2 offers a background to the study whilst Chapter 3 critiques the existing literature to undertake this research. Chapter 4 discusses the methodology used to underpin the study and Chapter 5 will discuss the methods applied. Chapter 6 presents an analysis of the data and findings from the study, following which Chapter 7 presents a discussion based on the results. Within this chapter an illustration of a proposed model for integrated care will be offered, including implications for practice, strengths and weaknesses of the study and considerations for further research. Chapter 8 presents an overarching conclusion to the study. This thesis culminates with a copy of a clinical academic paper based on the results of the study, an overview of the integration of knowledge, research and practice as developed in undertaking this Doctorate in Clinical Practice and a research log that defines the development of this study.
The following section offers an introduction to the context of palliative care and Cystic Fibrosis which reflects the topic to be examined. The chapter will conclude with a summary of this section.

1.2. Palliative care

There is evidence that palliative care should be available to all patients and their families irrespective of the stage of their disease or diagnosis (Standing Medical Advisory Committee 1992; Ahmed et al. 2004; O’Leary & Tiernan 2008; Weissman & Meier 2011). Palliative care is a sub speciality of medicine and refers to

“an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. It is applicable early in the course of an illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications” (WHO 2002 p.2).

It was recognised in 2010 that within the United Kingdom (UK) half a million people die each year and within that 36% die from cardiovascular disease, 27% die from cancer and 14% die from respiratory diseases (Barclay & Maher 2010). It is estimated that between 70% and 80% of all expected deaths are
likely to need palliative care input which would equate to around 355,000 people in England requiring palliative care every year (DH 2011).

1.3 Palliative care and Non-Malignant Disease

The ethos of palliative care has been embedded in, and grown from, the speciality of cancer (Clarke 2007). It was through the emergence of the Acquired Immune Deficiency Syndrome (AIDS) in the 1980s that questions relating to the provision of palliative care to those with a non-cancer illness emerged. Previously it had been recognised that patients dying from diseases other than cancer were experiencing symptoms that were not well controlled (Hinton 1963). Population based studies using random samples of deaths and relating to reports of bereaved carers, indicated that those patients with a non-cancer disease were likely to have more burdensome symptom problems in the last year of life, than those patients with a cancer diagnosis (Weatherall 2001; Murtagh et al.; 2004; Griffin & Conway 2008).

In 1992, an expert advisory group published recommendations that stated any patient with a life limiting illness should have access to palliative care services (SMAC 1992). The report suggested that a referral to palliative care should be based on the needs of patients rather than the disease type. The report referred to patients with no access to palliative care as “the disadvantaged dying” (Stewart & McMurray 2002). It was evident that historically palliative care had been developed with only those patients with cancer in mind (Addington-Hall et al.1998).
Resources to offer palliative care to all patients remain an issue for commissioners and the preliminary result of the palliative care funding review has highlighted a lack of transparency in the current palliative care payment system. This has resulted in providers not being incentivised to care for more patients due to the current block payment contracts (England PCT 2014). The issue of “distributive justice” falls into two categories, that of financial and manpower (Wasson & George 2001). Even with additional funding and resources that ensued with the End of Life Care Strategy in 2008 (DH 2008), there continues to be fundamental differences in offering palliative care services to those with cancer and those patients with other life limiting illnesses. The most common difference includes the difficulty in recognising when patients with non-malignant disease are dying. A lack of understanding around the pathophysiology of advanced disease and the availability of active treatments up until the end of life for patients dying from non-malignant diseases have been identified as contributing to the complexity involved in these patients (Dunlop 2001).

There is evidence that palliative care should develop new models of care to ensure services are meeting the needs of patients (Bourke. et al. 2009; Quill & Abernethy 2013). One way of aiming to achieve this is through an integrated model of care. The following section explores this as a model of care.
1.4. Integrated Care

Integrated care relates to principles for delivery of care that aims to improve the patient’s experience through improved coordination of care. Integration is the bringing together of methods, processes and models that help bring this about (Shaw et al. 2011). Planning integrated care involves teams having a shared vision and ensuring the patient’s perspectives are kept central throughout.

In the current climate of the National Health Service (NHS) quality and efficiency are paramount and experience outside of the United Kingdom recognises the impact integrated care can make in the delivery of efficient care (Shaw et al. 2011). To achieve an integrated service, connecting services is pivotal. Services and communication between Cystic Fibrosis and palliative care providers appear to be variable and the patient’s perception is relatively unknown as the literature review identified a focus towards end of life and bereavement studies. This study will add to this unknown area in understanding what is needed to develop an integrated approach to care. It is suggested that there is no one single model of integrated care that is appropriate for all situations and that clinicians should work together to define integrated services (Goodwin 2013). The need to see the complete picture through different lenses was integral to answering the research questions and understanding of what patients and professionals thought about the position of palliative care within the Cystic Fibrosis team.
The traditional model of palliative care grew from the speciality of cancer (Figure 1). The term terminal care was used to describe end of life care. There is no defined time on end of life care and this can range from the last twelve months of life to last few days or hours (DH 2008). Subsequent changes in definitions of palliative care suggest an integrated model of care where palliative care can be accessed any time throughout the patient’s disease journey.

**Figure 1. Models of Palliative care**

![Diagram showing traditional and integrated care models](image)

The American Society of Medical Oncology in 2009 released a vision for integrating Palliative care services in cancer that they would aspire to have in place by 2020 (Ferris et al. 2009). This indicated that as yet the cancer model is underdeveloped in its approach to integrated care.

There are five main types of integration considered in the literature namely systemic, normative, organisational, administrative and clinical (Kodner 2009; Rosen et al. 2011; Shaw et al. 2011). Systemic integration relates to coordinating and aligning policies, rules and regulatory frameworks such as
policy levers emphasising better coordinated care outside of hospitals, central impetus for diversity of providers, development of national incentive schemes (for example the Quality and Outcomes Framework) or financial incentives to promote downward substitution (Kodner 2009; Rosen et al. 2011; Shaw et al. 2011). Normative integration refers to the development of shared values, culture and vision across organisations, professional groups and individuals for example, developing common integration goals, identifying and addressing communication gaps, building clinical relationships and trust through local events, or involving service users and the wider community (Kodner 2009; Rosen et al. 2011; Shaw et al. 2011).

Organisational integration issues include coordinating structures, governance systems and relationships across organisations for example, developing formal and informal contractual or cooperative arrangements such as pooled budgets or practice-based commissioning; or developing umbrella organisational structures such as primary care federations or local clinical partnerships (Kodner 2009; Rosen et al. 2011; Shaw et al. 2011). Administrative integration issues relate to aligning back-office functions, budgets and financial systems across integrating units for example, developing shared accountability mechanisms, funding processes or information systems (Kodner 2009; Rosen et al. 2011; Shaw et al. 2011). Finally, clinical integration alludes to coordinating information and services and integrating patient care within a single process such as developing extended clinical roles, guidelines and inter-professional education, or facilitating the role of patients in shared decision-making (Kodner 2009; Rosen
et al. 2011; Shaw et al. 2011). All aspects of integration are significant for this study. In particular, the normative and clinical types of integration that aim to establish shared values, culture and vision and to be involved in building clinical relationships are important aspects to begin with as they set the scene for how services can be better coordinated. Other aspects will follow if these areas are introduced first. Having a shared vision and building and establishing relationships are fundamental to any changes in services. In addition to this it is evident that teams should look towards creating shared guidelines and education of what each team can provide (Shaw et al. 2011). As part of understanding the integration between the two teams it is necessary to establish the current relationship, and to determine perceptions of how palliative care is perceived by Cystic Fibrosis teams. This is necessary to understand what infrastructures would help support integration within these specialities.

Providing integrated care is described as being part of national and local government policy and that services have a duty to revise how they provide services and base them on quality effective care that enhances the needs and views of the patients (Shaw et al. 2011). This model of integrated care will be considered throughout this study.

1.5. Summary
The issue of patients with non-malignant disease requiring access to palliative care services is not new (Hinton 1963). Development of services and funding
of palliative care for all patients is under review within which the needs of the patient are seen as a priority to drive payment (England PCT 2014).

Integrated care should be considered as a way of developing new models of care. The following chapter will offer background information relating to the development of palliative care services and its position within non-malignant disease as well as exploring Cystic Fibrosis and justifying the rationale for the focus of this study.
CHAPTER 2: BACKGROUND TO THE RESEARCH

Following an opportunity for service development, the hospital Trust where the researcher worked was invited to provide the palliative care service to a neighbouring Trust where the specialty was heart and lung disease. At that time, the researcher had over twenty-five years’ experience in cancer and palliative care and was working in a large comprehensive cancer centre. The researcher had an interest in palliative care being offered to patients early in their disease trajectory for symptom control. As a result of this service development, the researcher, as the Nurse Consultant for palliative care, had a responsibility to scope the need for palliative care within the new service. On assessing the current provision of palliative care to patients with Cystic Fibrosis, and through talking to staff it became evident that access to palliative care services was limited and often only accessed for end of life care, if at all. The researcher became intrigued by this as observations on clinical visits demonstrated that patients with Cystic Fibrosis appeared to be in hospital for long periods of time throughout which they were burdened with symptoms including pain, cough, breathlessness, nausea and vomiting. This led to further discussions with experts in both Cystic Fibrosis and palliative care and thus the development of this study.

Cystic Fibrosis is one of the United Kingdom’s most common genetic life limiting illnesses and can result in death at an early age (Sawicki et al. 2008; Barr et al. 2011, Braithwaite 2011). It is an autosomal recessive disease caused by mutations in the cystic fibrosis membrane conductance regulator (CFTR) gene that results in abnormal transportation of sodium and chloride in
and out of cells leading to the production of thick sticky mucus in organs (Davies et al. 2007; Conway et al. 2008). Cystic Fibrosis usually presents in infancy with respiratory or nutritional symptoms (Mitchell 2000). The main systems affected are the respiratory and gastrointestinal tract and over time, chronic pulmonary infection and progressive pulmonary impairment become prominent features (Mitchell 2000). As the disease progresses other complications such as diabetes, liver disease, osteoporosis, arthritis and sinusitis may develop.

The management of Cystic Fibrosis requires daily and life-long treatments. These include physiotherapy to clear the lungs of sticky mucus, pancreatic enzymes to digest food, regular antibiotics, a high calorie diet and exercise (Edwards et al. 2013). Patients with Cystic Fibrosis face a number of symptoms including chest pain, cough, abdominal pain, breathlessness, haemoptysis, anorexia, depression, anxiety and the potential of requiring a lung transplant (Robinson 2011). With this burden of symptoms and uncertainty of the patient’s prognosis, the support that palliative care could offer early in the patient’s disease trajectory is relatively unknown and requires further exploration.

Lung transplantation is viewed as an end stage option for respiratory failure in patients with Cystic Fibrosis. Transplantation can offer hope to some patients for an improvement in symptom control, however for others the hope of a transplant can result in a lack of attention surrounding the progression of the disease (Robinson 2011).
The European Cystic Fibrosis standards in 2014 give reference to palliative care services and recognise the importance of raising end of life care issues, however this is only referred to when considering lung transplantation (ECFS 2014). This does, however, demonstrate a move towards Cystic Fibrosis services becoming more integrated with palliative care, as previous European standards in 2005 (Kerme 2005) did not recognise palliative care services being involved with this group of patients.

There are twenty three adult Cystic Fibrosis specialist centres within the United Kingdom providing specialist treatment to patients with Cystic Fibrosis. Historically few patients lived beyond early childhood but with the improvement in treatment modalities, quality of life and the life expectancy of the person with Cystic Fibrosis have improved. Over the last twenty years these improvements have resulted in patients living longer with Cystic Fibrosis with an identified need for Palliative care for symptomatic management (Sawicki et al. 2008; Stenekes et al. 2009; Wiehe & Amdt 2010; Braithwaite et al. 2011). The most recent available data in the United Kingdom confirmed that over 9,000 patients were registered as having a diagnosis of Cystic Fibrosis. Table 1 illustrates the number of patients with Cystic Fibrosis as reported by country.
Table 1. Numbers of patients with Cystic Fibrosis reported by each country in 2010

<table>
<thead>
<tr>
<th>Country</th>
<th>2010</th>
<th>Estimated Coverage</th>
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<tbody>
<tr>
<td>Austria</td>
<td>511</td>
<td>57%</td>
</tr>
<tr>
<td>Belgium*</td>
<td>1138</td>
<td>&gt;90%</td>
</tr>
<tr>
<td>Czech Republic*</td>
<td>523</td>
<td>100%</td>
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<tr>
<td>Denmark*</td>
<td>450</td>
<td>100%</td>
</tr>
<tr>
<td>France*</td>
<td>5759</td>
<td>90%</td>
</tr>
<tr>
<td>Germany*</td>
<td>5003</td>
<td>95%</td>
</tr>
<tr>
<td>Greece</td>
<td>96</td>
<td>20%</td>
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<tr>
<td>Hungary*</td>
<td>557</td>
<td>90%</td>
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<td>Israel*</td>
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<td>Italy*</td>
<td>4119</td>
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<tr>
<td>Latvia</td>
<td>30</td>
<td>&gt;90%</td>
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<tr>
<td>Rep of Moldova*</td>
<td>42</td>
<td>100%</td>
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<td>The Netherlands *</td>
<td>1306</td>
<td>97%</td>
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<tr>
<td>Portugal</td>
<td>138</td>
<td>48%</td>
</tr>
<tr>
<td>Russian Federation</td>
<td>359</td>
<td>15-20%</td>
</tr>
<tr>
<td>Serbia</td>
<td>121</td>
<td>&gt;90%</td>
</tr>
<tr>
<td>Slovak Republic*</td>
<td>333</td>
<td>&gt;90%</td>
</tr>
<tr>
<td>Slovenia</td>
<td>80</td>
<td>75%</td>
</tr>
<tr>
<td>Spain</td>
<td>918</td>
<td>30%</td>
</tr>
<tr>
<td>Sweden*</td>
<td>509</td>
<td>80-85%</td>
</tr>
<tr>
<td>Switzerland</td>
<td>443</td>
<td>55%</td>
</tr>
<tr>
<td><strong>United Kingdom</strong>*</td>
<td><strong>9385</strong></td>
<td><strong>100%</strong></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>32248</strong></td>
<td></td>
</tr>
</tbody>
</table>

*Represents countries who have a national registry (European Cystic Fibrosis Society 2010)

The column labelled estimated coverage shows the estimated percentage of patients with Cystic Fibrosis living in those countries that are included in the national registries/national data collections.

A summary of patients registered with Cystic Fibrosis (CF) from the United Kingdom (UK) registry between 2009-2014 is displayed in Table 2 showing an increase since 2009.
Table 2. Summary of Cystic Fibrosis United Kingdom Registry 2013

<table>
<thead>
<tr>
<th>Summary of the United Kingdom Cystic Fibrosis Registry</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>CF patients registered excluding diagnoses that year</td>
<td>9029</td>
<td>9385</td>
<td>9749</td>
<td>10078</td>
<td>10338</td>
</tr>
<tr>
<td>CF patients with complete data</td>
<td>7377</td>
<td>7937</td>
<td>8679</td>
<td>8794</td>
<td>9052</td>
</tr>
<tr>
<td>Age at diagnosis in months; Median</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Median predicted Survival in years (95% CI)</td>
<td>34.4</td>
<td>41.4</td>
<td>41.5</td>
<td>43.5</td>
<td>36.6</td>
</tr>
<tr>
<td>Total Deaths reported</td>
<td>141</td>
<td>103</td>
<td>118</td>
<td>196</td>
<td>146</td>
</tr>
<tr>
<td>Age at death in years; (95% CI)</td>
<td>27</td>
<td>29</td>
<td>26</td>
<td>28</td>
<td>29</td>
</tr>
</tbody>
</table>

CF/UK Trust (2013)

Transplant can be considered for some patients and Table 3 below illustrates the number of patients referred for transplant and also represents the number of patients who have received a transplant.

Table 3. Transplant Activity in United Kingdom

<table>
<thead>
<tr>
<th>Transplant Activity</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of patients with annual review data evaluated for transplants</td>
<td>143</td>
<td>169</td>
<td>204</td>
<td>225</td>
<td>220</td>
</tr>
<tr>
<td>Numbers accepted on the transplant list</td>
<td>79</td>
<td>82</td>
<td>121</td>
<td>120</td>
<td>136</td>
</tr>
<tr>
<td>Numbers receiving transplants (&gt; 16)</td>
<td>22*</td>
<td>26</td>
<td>48</td>
<td>52**</td>
<td>54*</td>
</tr>
<tr>
<td>Bilateral Lung</td>
<td>16</td>
<td>24</td>
<td>40</td>
<td>43</td>
<td>48</td>
</tr>
<tr>
<td>Heart and Lung</td>
<td>0</td>
<td>1</td>
<td>4</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Liver</td>
<td>5</td>
<td>0</td>
<td>2</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>4</td>
<td>4</td>
</tr>
</tbody>
</table>

*One patient received 2 transplants
**Two patients had 2 transplants

CF/UK Trust (2013)

Although the age at death has increased, patients continue to have a reduced life expectancy with a median age of death of 29 years. In terms of patients with Cystic Fibrosis receiving transplants it is evident that the number of
bilateral lung transplants has increased from 16 in 2009, to 48 in 2013 (CF/UK Trust 2013). However, not all patients who are identified as needing transplants will be accepted onto the transplant list as illustrated in Table 3. Regardless of whether a patient with Cystic Fibrosis is accepted onto the transplant list or not, the involvement of palliative care service providers is unclear.

The need to acknowledge the potential unmet need of patients dying from life limiting illnesses other than cancer has been well documented (Hinton 1963; Addington-Hall 1998; Murray et al. 2002; Braithwaite et al. 2011). Various National Service Frameworks (NSF) refer to patients from groups other than cancer requiring access to palliative care services. These groups included Chronic Obstructive Pulmonary Disease, Heart Failure, Renal Disease and those with Neurological diseases (DH, 2000; DH 2004; DH 2005; DH 2008). Cystic Fibrosis has transitioned into a chronic illness and supporting patients living with symptoms caused by the disease could be offered by palliative care services. The acceptability of how this would be for patients with Cystic Fibrosis and staff in palliative care delivering the service is relatively unexplored.

2.1. Trajectory of Palliative Care

The historical perspective of the integration of cancer and palliative care relates to the implementation of palliative care in the last few days or weeks of a patient’s life and was often referred to as terminal care (Clark 2007). This
supported the WHO definition in 1990 when palliative care was viewed as a service for patients at the end of life. With the updated definition in 2002 current palliative care aims to offer services based on needs of patients rather than the stage of disease and has extended to both cancer and non-cancer patients. The introduction of guidance in 2004 from the National Institute for Heath and Care Excellence (NICE 2004), recommended that patients should be able to access palliative care support whilst having investigations prior to a confirmed diagnosis and that this should be referred to as supportive care. Patients would therefore, at earlier stages of their illness, have access to supportive care.

It has been acknowledged that there is overlap between supportive and palliative care services and this has, for some professionals, resulted in confusion (NICE 2004; National Council for Palliative Care (NCPC) 2006). The more integrated trajectory suggests that palliative care should be involved at the earlier stages of the patient’s illness (Pitcher & Davis 2001). Evidence suggests that in some circumstances diseases such as HIV or Cystic Fibrosis will require highly technical interventions that are appropriate to run alongside palliative treatment with each becoming dominant at different stages of the disease process (Goldman & Schuller 2001).

Currently palliative care offers a comprehensive service for people with cancer. For those with a non- malignant disease palliative care services are continuing to develop (Andrews & Seymour 2011). It has been identified that there are large numbers of patients with a non-malignant disease who have
problems that are as equally distressing as those experienced by cancer patients and who would benefit from palliative care support (Addington-Hall et al. 1998). The service model for patients with non-malignant disease is not as well developed as in the case of patients with cancer.

The purpose of this research is to explore how patients with Cystic Fibrosis and professionals from both Cystic Fibrosis and palliative care perceive early palliative care and the perceptions and understanding what a referral to a palliative care service means for them. Understanding what professionals and patients think about a palliative care service will help the development of models of care in the future between Cystic Fibrosis and palliative care. In order to differentiate between palliative and supportive care the following section will offer definitions in addition to the background relating to policy affecting palliative care in the Cystic Fibrosis population.

2.2. Definition of Palliative care

The first definition of palliative care, which has subsequently undergone several iterations, was in 1990. The definition stated “palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the “best possible quality of life for patients and their families” (WHO 1990 pp.94). In 2002, the definition had a further iteration as described previously in Section 1.2. This current definition also includes patients
undergoing additional investigations to allow a better understanding of the stage and complexities of the disease process.

The difference between the two definitions relates to palliative care being involved with patients who may not die, and being involved with therapies to prolong life. There remains no definition of when “early” palliative care should start but the perception and interpretation by professionals in the field of cancer, was that palliative care should be offered in parallel with anti-cancer therapies.

2.3. Definition of Supportive Care

The term supportive care was first alluded to in 1994 and was used to describe a comprehensive programme to meet patients need from an holistic point of view and was available to patients, pre diagnosis, at diagnosis, during treatment and through the follow up phase (Fitch 1994). Supportive care included patients with cancer who required symptom control and also others with life limiting illnesses (Fitch 1994; NCPC 2006). A systematic review recognised that best supportive care is considered by professionals to be the same as palliative care (Hui et al. 2013) and for patients in a randomised controlled trial they found it easier to describe supportive care in their own words as opposed to palliative care (Maciasz 2013). A further study established that the term palliative care has become more commonly used and has increased in use over time, whereas the frequency of use of the term supportive care has remained the same (Hui et al. 2013). This may signify
professionals recognising the need to be consistent in the terminology applied. It is clear from the definitions available that there is a lack of consensus regarding what palliative care actually is. This has resulted in the timing of referral to palliative care becoming increasingly complex especially for the professionals caring for the patients with Cystic Fibrosis.

Supportive care is provided to people with cancer and their carers throughout the patient pathway from pre-diagnosis onwards (NICE 2004). The term supportive care was used in relation to adults with cancer; however with slight modification in the terminology it is applicable to anyone with a life limiting illness (NCPC 2006). By definition, this would be applicable to those patients with Cystic Fibrosis. Supportive care is an over-arching term for all palliative care services, both generalist and specialist, that may be required to support people with cancer and non- malignant conditions and their carers. It is not a response to a particular stage of disease, but is based on an assumption that people have a need for supportive care from the time that a possibility of cancer or other life limiting illness is first raised. It was recognised that palliative care should become a gradually increasing part of care from diagnosis to death, rather than being concerned only with the terminal phase (Higginson 1993).

Having a number of different definitions of both supportive care and palliative care has resulted in a considerable degree of confusion, not only for health professionals but also for patients. Not only are many people unsure about what palliative care is, and when it should be provided, but also confusingly
that palliative care is, in some circumstances, part of supportive care and vice-versa (NICE 2004; NCPC 2006).

Many people have only heard about palliative care as something that is provided in hospices for people who are dying (Addington-Hall & Higginson 2001; Ahmed et al. 2004; NICE 2004; Walsh et al. 2008). Offering palliative care early in the course of a disease is not without difficulty. Some people refuse the offer of palliative care believing that to accept it will mean that they are going to die (Ward et al. 2009). They may also believe that they will no longer be offered any disease modifying or curative treatment. Whether the terminology refers to supportive or palliative care the experience of someone faced with a life limiting illness is different for each person with each having a unique need for information, support and care.

The introduction of supportive care as well as palliative care has often led to confusion regarding the timeliness of referrals to palliative care. For professionals there remains at times a direct association between referral to palliative care and an association with death (Ahmed et al. 2004). There remains concern from professionals that referral to palliative care will result in patients giving up hope and that the focus of palliative care will be around death (Johnson et al. 2008).

For this study palliative care is defined as a service that can become involved with patients at any stage of their illness and is based on need rather than diagnosis or stage of disease as previously defined by WHO (2002).
2.4. The Confusion of Language to Describe Palliative care

Palliative care appears to be struggling with its identity and patients and health care professionals either have no knowledge about palliative care or believe it is synonymous with end-of-life care (Parikh et al. 2013). Palliative care is appropriate at any stage of a serious illness, and can be provided together with curative treatment. Several clinical trials have shown benefits of early palliative care in patients with advanced cancer (Temel et al. 2010; Greer et al. 2013). The effect of early palliative care on other non-malignant patient populations is less well researched.

There is to date, a myriad of terms used to describe palliative care. In 2013 Hui et al. identified twenty four different definitions of palliative care. Some of these terms include care of the dying, terminal care, supportive care, hospice care, comfort care and actively dying. The term palliative care was derived in 1973 from Balfour Mount who was looking for a name to call a terminal care ward. As the phrase terminal care was already in existence he used the term palliative care to replace terminal care. Criticism for this ensued with challenges being made to the creation of a euphemism for terminal care (Doyle 1993; Billings 1998).

2.5. Policy Development

In the United Kingdom a report entitled “The Principles and Provision of Palliative” care identified by the Standard Medical Advisory Committee in 1992 acknowledged “the disadvantaged dying”, and referred to those dying from diseases other than cancer. The document highlighted that patients with life
limiting illnesses other than cancer should be able to access palliative care services (SMAC report 1992). The Calman-Hine Report (DH 1995) although focused on a policy framework for commissioning cancer services subsequently led to a review of palliative care services. The historical development of palliative care is illustrated in Table 4 below as discussed within the palliative care literature.

Table 4. Timeline of Palliative care Development

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Development of home for the dying (Lyon, France) • Development of home for the dying (Hackney, London)</td>
<td>• Macmillan established further work in 1970 to support cancer services • Marie Curie Nursing Homes developed</td>
<td>• Patients with non cancer demonstrating similar distress as those patients with cancer • Hospice opened Sydenham, London by Dame Cicely Saunders</td>
<td>• Hospital support teams for terminal care were pioneered in the UK</td>
<td>• SMAC report identified distress of those dying from non cancer diseases • HIV identified and raised awareness for Palliative care for patients with non cancer</td>
<td>• British Government appoint a National Director to inform and improve cancer services • Publications relating to Palliative care and non cancer plentiful in the literature</td>
<td>• NICE - Supportive and Palliative care Guidelines • Department of Health End of Life Care Strategy launched (for all patients who are dying irrespective of disease)</td>
</tr>
</tbody>
</table>

(Adapted from Clark 2000)

The development of both the guidance on supportive and palliative care for Adults with Cancer (NICE 2004) and the National End of Life Care Strategy (EoLC), (DH 2008) were significant in the management of patient care and service development. The supportive and palliative care guidance acknowledged involving palliative care services earlier in the patient’s cancer illness referring to this as supportive care, whilst also recognising the need to
support patients at the end of life (NICE 2004). Although written for cancer patients, it was recognised that with a slight change to the definition of supportive care all patients should have access to palliative care at any stage of their illness (NCPC 2006). The EoLC strategy was produced with a plan to be implemented by the National Health Service (NHS) working in collaboration with local authorities and with support from the Department of Health (DH 2008). It was referred to as being the first comprehensive framework which was aimed at promoting high quality care for all adult patients approaching the end of their lives including cancer and other life limiting illnesses (DH 2008).

The EoLC strategy was supported financially by the then Labour Government. A potential unintended effect of the EoLC strategy is in the association of palliative care with death and increased public awareness of this association. The focus relates, primarily, to the end stages of a patient’s life. The strategy encourages patients to choose to die where they wish, which in the majority of cases is home (NCPC 2011). Whilst this is supported by clinicians there was limited funding to support this to happen, therefore palliative care services have had to increase provision to allow patients to die at home. With limited resources this could inhibit the availability of palliative care services to support patients earlier in their disease trajectory as the focus was to support patients who were dying.

### 2.6. Cystic Fibrosis and Palliative care

There has been limited exploration in the UK on the involvement of palliative care early in patients with Cystic Fibrosis’ disease trajectory to support
symptom management. Rather, studies looking at end of life care and advance care planning for adults with Cystic Fibrosis have been conducted (Mitchell et al. 2000; Chapman et al. 2005; Iles & Lowton 2008; Sawicki et al. 2008). It is known that potentially this is a group of patients who may benefit symptomatically from either direct support from a palliative care team or indirect through support and advice to Cystic Fibrosis professionals (Bourke et al 2009; Braithwaite et al. 2011). Pain, breathlessness and cough have been recognised as being significant problems for patients with Cystic Fibrosis (Stenekes et al. 2009).

The contribution that palliative care services can make towards the control of patients symptoms has been recognised within the literature (Edmonds et al. 1998; Klepstad et al. 2005; Stevens et al. 2005; APM 2012). In a retrospective review looking at predictors of access to a palliative care service it was identified that 499 out of 1453 (34%) patients had access to palliative care services. It was indicated that palliative care services can help in supporting those patients who have physical and psychological distress but that referral patterns should be more clearly defined (Fadul et al. 2007).

There are several possible reasons for variability in the pattern of referral to palliative care. These reasons include different patient needs, variability in the referrer and possible perceptions of patients towards the palliative care referral and ongoing care (Catt et al. 2005; Burt & Raine 2006; Ewing 2009). From a professional viewpoint lack of knowledge or skill may trigger a referral or alternatively may prevent a referral from occurring (Bestall et al. 2002;
Bradley et al. 2002; Aitken 2006). In earlier studies education and training for professionals were observed as facilitating referrals to palliative care services (Schim et al. 2000; Friedman et al. 2002). Therefore understanding what patients with Cystic Fibrosis think about palliative care and those caring for them will be instrumental in developing new models of care.

2.7. Summary

Cystic Fibrosis is a chronic life limiting illness that is rising in the United Kingdom. The average age at death remains at 29 years. Policy development since 1992 has mentioned patients with diseases other than cancer and their unmet needs. There is some existing confusion around the definition of supportive and palliative care that can result in uncertainty as to when it is appropriate to refer patients to a palliative care service. The definition of palliative care from the World Health Organisation, (WHO 2002) has been selected to underpin this research as it encompasses the ethos of access to palliative care at different times in the patient’s journey and supports patients having ongoing active treatment. Research is needed to explore the experiences and perceptions of patients with Cystic Fibrosis and of health care professionals regarding palliative care. The acceptability of palliative care as a service early in the Cystic Fibrosis patient’s disease trajectory needs to be explored.
CHAPTER 3: LITERATURE REVIEW

3.1. Introduction

The following chapter will explore and critically appraise existing evidence that has been used to support the development of the research questions. Whilst the researcher recognised that she had expert knowledge in palliative care she had limited knowledge of Cystic Fibrosis and therefore had limited pre conceived ideas regarding available literature. However it is recognised that most researchers will have some pre conceived ideas about the topic to studied (Bryant & Charmaz 2007). It was necessary to review the literature from both the patient and professional perspectives to see if any other study had researched views of palliative care from patients and health care professionals. Exploring the literature to identify if patients and health care professionals had previously been asked regarding timing of referral to palliative care was essential.

The interest in this topic had arisen from clinical exposure to patients with Cystic Fibrosis. Reviewing the literature relating to symptom control issues for patients with Cystic Fibrosis was necessary to ensure the researcher’s observations were not circumstantial. In the clinical setting it had been observed that patients with Cystic Fibrosis were symptomatic from their disease and admitted to hospital for long periods of time but it was evident that palliative care was not always involved. In considering the way to approach the literature review it was necessary to consider the position of non- malignant diseases within palliative care and to consider barriers and
access to this group towards palliative care services. Literature relating to palliative care and Cystic Fibrosis was also reviewed. This chapter will discuss the literature found and will offer an overview of search strategies used and the tools used to guide analysis of the research literature. The chapter will end with a summary of the gaps in the literature and a rationale for research questions developed the methodology and the selected research design.

3.2. Search Strategies

Figure 2 illustrates the search strategy applied for this literature review. Key phrases and MeSH terms were applied to the searches.

**Figure 2. Searched Databases**

The search included accessing the databases listed in Figure 1. The databases were accessed from 1980-2014. The rationale for this was that palliative medicine did not become a sub speciality of medicine until 1986.
Search terms included:

Cystic Fibrosis and Palliative Care
Perceptions of Palliative care in Patients with Cystic Fibrosis
Perceptions of Palliative care/Professionals Views
Timing of referral to Palliative Care in Cystic Fibrosis/Non-Malignant Disease
Non-Malignant disease and Palliative Care
Barriers of referral to Palliative Care
Integrated Care in Cystic Fibrosis and Palliative Care
Models of care in Palliative Care and Cystic Fibrosis

English language studies were included and review articles were included if Cystic Fibrosis was mentioned or had relevance to chronic chest conditions and involvement of palliative care. Searches were limited to adult references only and children and adolescent literature were excluded. Where there was no evidence available between Cystic Fibrosis and palliative care the researcher looked to other non-malignant conditions where patients with Cystic Fibrosis might have been included. Critical appraisal skills programme (CASP) questions were used to support appraisal of both the qualitative and quantitative research articles (CASP 2006). These tools were used as they support the appraisal of both qualitative and quantitative research studies.

Figure 3 below illustrates the articles reviewed.
Figure 3. PRISMA Diagram of Articles Searched and Reviewed

Records identified through database searching (n = 28,543) → Records after duplicates removed (n = 28,462)

Records screened (n = 28,462) → Records excluded (n = 28,312)

Full-text articles assessed for eligibility (n = 170) → Full-text articles excluded, with reasons (n = 118) (75 related to paediatrics only, 30 related to interventions in CF, 13 unrelated to CF or PC in context of study)

Studies included in qualitative synthesis (n = 25)

Studies included in quantitative synthesis (n = 14)

Review articles: 11
Concept Analysis: 1
Mixed Methods: 1
3.3. Cystic Fibrosis and Palliative care

The search between Cystic Fibrosis and palliative care was interesting as the majority of the articles sourced related to Cystic Fibrosis and end of life care. Although palliative care was inputted to the search engines in many instances end of life care was mentioned in the title and within the abstract. These articles have been included due to the understanding of palliative care and its definition as equating to death and dying.

3.3.1. Timely introduction of Palliative care Services

Within Cystic Fibrosis there has been limited exploration on the involvement of palliative care early in the patients’ disease. Studies looking at end of life care and advance care planning for adults with Cystic Fibrosis have been conducted (Mitchell et al. 2000; Chapman et al. 2005; Iles & Lowton 2008; Sawicki et al. 2008). The study by Chapman et al. in 2005 focused on end of life care in adult patients with Cystic Fibrosis. Interviews were conducted with patients, staff and relatives. The results of this study indicated that the staff felt they had open communication about end of life care and with psychological input staff felt supported. The concern of patients being actively managed and receiving palliative care at the same time was raised by staff as an issue. The patient’s annual review was raised by professionals as being a place to discuss end of life care. The authors of this study conclude that providing active and palliative care at the same time can occur up to the time of the patient’s death. They suggest that this results in there being less need to bring in other sub specialities for end of life care although they did acknowledge that the palliative care team was available for advice on symptom control. The
article does not discuss how the palliative care team would become involved, whether it would be advisory to the Cystic Fibrosis team only, or if they would in fact review the patient. It is unclear if patients’ having a relationship with the palliative care team is of any significance. This study used interviews to collect data which is an acceptable way to explore sensitive areas such as end of life care which can cause unanticipated distress to participants.

The study by Iles and Lowton in 2008 interviewed young people to try and establish when and who should address the concerns of people with Cystic Fibrosis. Patients internalising concerns about the future were identified as well as staff concerns regarding discussing the future with the patients. At no time was palliative care mentioned as a potential resource to help with patients or to support staff. This study highlights the limited input from palliative care services.

A study by Lowton (2009) explored meanings of place of death for adults with Cystic Fibrosis. This research involved in depth interviews and analysis of letters received from parents of twenty seven adults who had died from Cystic Fibrosis during a four year period. Letters were forwarded by the Cystic Fibrosis Trust to 275 families; however the authors recognised that many families break all links with the Trust once someone has died which may have inhibited participation. Whilst the focus of this study related to end of life care interesting information is made available to the way in which palliative care was introduced to some families. In one instance a mother recounts how two hours before the death of her daughter she was asked to meet the palliative
care nurse for the first time. In this extract the opportunity to be reviewed by palliative care was declined by the participant as she chose not to meet a stranger at that time. This illustrates that introducing palliative care at this stage may be too late for families and may be the same for patients. There are no research studies available to clarify what patients perceive as a good time to be introduced to palliative care teams which signifies a gap in the literature in this area and supports further exploration of this topic.

In 2000 Mitchell et al. research surveyed Cystic Fibrosis physicians to ask them about circumstances in which patients died the role of different caregivers and the extent to which palliative care was involved. Forty five completed questionnaires were returned, based on the numbers of deaths in the time period. The results from this study highlighted that in 25% of cases palliative care had never been discussed and in 40% of cases palliative care was not discussed until four weeks before the patient's death. The research states that palliative care/comfort measures were applied in 76.3% but does not discuss if these measures were used as a result of integrated working or if this was initiated by the Cystic Fibrosis team. This study acknowledged the perception of palliative care being to stop unpleasant treatments in diseases such as AIDS or cancer and how patients with Cystic Fibrosis require active treatments up until the end of life. They also state that this can make it difficult for clinicians to identify the right time to transition from active to palliative treatment. This final statement does not recognise the option of Cystic Fibrosis and palliative care working together in an integrated model of care. It
is viewed as either one or the other and leaves the reader open to considering that palliative care would not concur with active treatments.

The challenge of active and palliative care working together is discussed by Clisby et al. (2013). A qualitative explorative design was used and ten interviews with staff working in Cystic Fibrosis were undertaken to research the psychological impact of working with patients with Cystic Fibrosis at the end of life before transplant. One of two themes that emerged from the data analysis was the difficulty for staff in juggling both the acute and palliative side of care for patients. It was indicated that the relationship between the patient and the professional is deepened through this time especially when staff are working closely with the patients and that this may also be related to their similar ages. This article recognised the importance of relationships between those delivering and receiving care but was limited in terms of directing health care professionals regarding how best to overcome the issue of Cystic Fibrosis and palliative care working concurrently.

3.3.2. Cystic Fibrosis and Symptom Control
The literature review highlighted that patients with Cystic Fibrosis may benefit symptomatically from either direct support from a palliative care team or indirect through support and advice to Cystic Fibrosis professionals and that palliative care in Cystic Fibrosis is poorly understood (Bourke et al. 2009; Braithwaite et al. 2011). The study undertaken by Braithwaite involved interviewing staff, patients and families with the focus being on determining unmet needs in end of life care. Although within this study it was recognised
that patients lacked knowledge about palliative care services, there was no discussion about what type of service the patients would like. The questions to inform the interviews were focused towards end of life and did not include asking the patients about when would be a good time to consider being introduced to the palliative care team. Staff acknowledged that they felt a more integrated care system would be better for them and the patients but recognised that they felt there was an unwritten rule that they were expected to cope with patients’ needs without additional support. This study was limited by the lack of patient views on when would be best to meet the palliative care team.

Pain, breathlessness and cough have been recognised as being significant symptom problems for patients with Cystic Fibrosis (Stenekes et al. 2009). In this study 123 participants completed a survey which produced a response rate of 64%. Of the participants who did respond 84% had pain, 64% reported breathlessness and 83% reported experiencing a cough. The survey questions did not include the stage of the patient’s illness but irrespective of this the level of symptom burden would suggest a review by a palliative care specialist for assessment of symptoms to be appropriate. This research contributes to the understanding of symptoms experienced by patients with Cystic Fibrosis but does not offer any suggestions in how to manage them.

A further study by Kelemen et al. (2011) recognised that patients with Cystic Fibrosis have pain that can limit the ability to undergo important physiotherapy sessions. In this observational study of 73 patients the authors demonstrated
that mild pain was reported in 89% of patients with stable disease and 79% of patients who were having an exacerbation of their disease. There was no reference to how the pain would be managed other than a suggestion that clinicians may need to be forward thinking in initiating pain treatments to support the patients. There was no mention of working alongside other services such as pain or palliative care services. The literature also identified that due to the high prevalence of low bone mineral density in patients with Cystic Fibrosis were at an increased risk of bone fractures. Rib fractures have been recognised as occurring after coughing and can be difficult to gain symptom relief (Haworth et al. 1999; Conway et al. 2000; Jones et al. 2001; Dean et al. 2014).

A literature review by Havermans et al. (2013) explored thirteen studies that commented on pain in Cystic Fibrosis. Abdominal and chest pains were stated as being the most frequently reported sites of pain. This review acknowledged that pain control for patients with Cystic Fibrosis has no guidelines and assessment tools are lacking to support treatment plans. The authors also recognised how inadequate pain control can limit active treatment for patients such as physiotherapy. There was no discussion relating to who outside of the Cystic Fibrosis team could perhaps help support both patients and staff with the development of guidelines and assessment tools.

In 2004, Festini et al. recognised following a survey of 239 adults with Cystic Fibrosis that there was a high prevalence of painful episodes with almost a third of patients having over ten episodes of pain. The most commonly
referred to pain was headache, gastrointestinal pain and backache. In this study just over 40% of patients asked for help from the Cystic Fibrosis specialists and 3.5% asked for help from their General Practitioner. In this paper there was no discussion of other services that could help with pain control.

Self-reported physical and psychological symptom burden of adults with Cystic Fibrosis were studied by Sawicki et al. (2008). In this research patients were invited to complete a validated symptom burden tool to assess their symptoms. There were 303 respondents which offered an excellent 91% response rate. Within this study it was recognised that the most common symptoms were cough (94%), breathlessness (77%) and lack of energy (77%). In addition to this over half of the patients reported psychological issues such as worrying, feeling irritable and feeling sad. The introduction of a thorough symptom assessment is concluded in this paper however there was no plan as to how to integrate with other services. It was clear from this study that patients with Cystic Fibrosis do have symptom control needs that could be further optimised through support from palliative care.

A study in Australia explored unmet need in patients with Cystic Fibrosis, their families and carers. In total there were forty two participants involved in interviews and focus groups. Following thematic analysis this study identified 6 themes. It was recognised that maintaining hope and planning for death was a particular challenge for patients, families and staff (Braithwaite et al. 2011). The research did not consider if palliative care inhibited maintaining hope and
concluded that access to palliative care should increase but did not suggest how that should evolve.

These findings are further supported by the responses of 27 bereaved caregivers who were interviewed regarding symptoms and treatments. The interviews took place with the carers of family members who had died in the last 4 years. The actual time between death of the family member with Cystic Fibrosis and the interview is not discussed within the paper. This does bring into question the accuracy of recall in carers who may have experienced a death 4 years previously. Caregivers identified that breathlessness (100%), fatigue (96%), anorexia (85%), anxiety (74%); pain (67%) and cough (56%) were the most common symptoms experienced. They also expressed a belief that symptoms could not be controlled and were concerned about the role of opioids such as morphine and their potential for hastening death (Dellon et al. 2010).

3.4. Palliative care and Non-Malignant disease

The literature relating to palliative care and non-malignant disease was reviewed to determine if Cystic Fibrosis was acknowledged within the literature and to ascertain how palliative care relates to other diseases other than cancer.

A study by Murtagh et al. (2014) looked at how many people needed palliative care. The study design was founded on refinement of existing population
based methods based on the views of an expert panel and application and
comparison of existing and refined approaches in an example dataset. This
study looked at all deaths in England between the years 2006-2008. The
results of this study demonstrated that an expert panel suggested changing
practice and extending palliative care to include more non-malignant
conditions and to also change working patterns in the hospital and home care.
This study highlighted the need for palliative care to further develop services
for patients with non-malignant disease but how to enable this was unclear.

In determining how palliative care has evolved, a concept analysis
demonstrated that there was progress towards embracing a definition of
palliative care that involved being accessible at any stage of a patient's illness
(Meghani 2004). However it was also recognised that health care
professionals continued to use the term palliative care interchangeably with
end of life care. This research acknowledged that palliative care has evolved
to include a wide range of different patient groups who that not are dying but
that may require access to palliative care services to improve quality of life.
The author discusses the importance of new models of care to meet the
demands of patients and success would depend on integrating the changing
face of Palliative care into daily practice. This research is significant in
considering, for the researcher, what current models of care exist between
Cystic Fibrosis and palliative care.

Identifying the needs of patients with non-malignant disease was recognised
in 1998 by Addington-Hall et al. In this study a secondary analysis of data
from a retrospective national population based interview survey was presented. A total of 3,696 patients were randomly chosen from death registration, this occurred late in 1990. The results of this study showed that for the patients who had died with a non-malignant disease 16.8% had reported symptoms similar to patients with cancer in the last year of life. It was estimated that caring for the projected numbers of patients with non-malignant disease who would need access to specialist palliative care would require an increased caseload of at least 79%. At this time it was recommended that clinicians working with patients with non-malignant disease should work closely with palliative care services, commissioners, including commissioners to develop services which meet the needs of patients for symptom control and psychosocial support.

The unmet need of patients with non-malignant disease was described in a study by Currow et al. (2008). This was part of a wider randomised face to face population health survey over six years. Questions were asked of people bereaved in the previous five years when someone close to them had an expected death. These results illustrated that uptake of palliative care services was significantly lower in people with a non-malignant disease. This study also stated that carer responses had suggested that for other groups of patients poor uptake of palliative care services did not always equate with an unmet need in patients; however the same pattern did not follow in patients with non-malignant disease.
Palliative care services for those with chronic lung disease were studied by Fitzsimons et al. (2007). In this study the aim was to explore palliative care needs of non-cancer patients from the patient’s perspective using a mixed methodology. Eighteen patients were interviewed, six of whom had a respiratory condition. The actual diagnosis was not stated for the participants and therefore the researcher is unable to determine if patients with Cystic Fibrosis were included. The results from this study confirmed that patients dying from chronic illnesses had many concerns and unmet clinical needs. The authors confirmed the need for an earlier implementation of palliative care for patients but did not highlight how to implement this.

A further study examined the experience of patients with non-malignant disease (McKechnie et al. 2010). This group of participants included patients with diseases representing respiratory, renal, cardiac, cancer and neurological disease. Thirteen patients were interviewed in this study with eight carers and five professionals. A limitation of this study is that of the patients only three had respiratory disease and did not state what disease type the patients had therefore the researcher is unable to say if Cystic Fibrosis was represented in this group. The results of this study demonstrated that patients with non-malignant conditions make similar demands on professionals and their families/carers as those with a diagnosis of cancer. This study also focused on end of life care and did not discuss palliative care being accessed earlier for patients or integration with other services.
In identifying the need of patients with a non-malignant disease a literature review of 14 studies undertaken by Luddington et al. (2001) reported that patients had similar physical and psychosocial needs compared to patients with cancer. The focus of this review was on patients dying from non-malignant diseases but acknowledged that achieving equity for this group of patients may be difficult to achieve as palliative care services may become overwhelmed by numbers of referrals. This review discussed a model of developing shared care between the primary and palliative care teams but no guidance as to how this should be offered.

In the same year (2001) Edmonds et al. published a study comparing the palliative care needs of patients dying from chronic respiratory diseases and lung cancer. This study involved post bereavement structured interviews with informal carers of 449 lung cancer patients and 87 chronic lung disease patients. It is clear that the diagnosis of patients who had died did not include anyone with Cystic Fibrosis. However in the results of this study it was acknowledged that patients with chronic lung disease appeared to have experienced symptoms for a longer time period in comparison with the lung cancer group. It is interesting that Cystic Fibrosis as a group were not represented in this study perhaps indicating that the level of need had not yet been realised.

A study by Pinnock et al. (2011) researched the views of patients living and dying with chronic obstructive airways disease. The study involved serial qualitative interviews with patients, carers and professionals. The results
highlighted that symptom burden was accepted as part of living with a lifelong condition. As in other studies this research equated to studying end of life care in this group of patients. In the conclusion the authors recognised that trying to find the correct time-point to introduce palliative care to these patients could be counter-productive as it may inhibit patients being able to access supportive and palliative care earlier in their disease trajectory. The authors suggest that patients should be assessed at key disease milestones such as after hospital admissions or after an exacerbation of their disease. This would then facilitate supportive and palliative care becoming more integrated with these patients. There was no discussion regarding patients with Cystic Fibrosis in this research, however some of the milestones are similar in terms of hospital admissions and episodes of exacerbation.

Dharmasena & Forbes (2001) questioned if physicians would refer patients with non-malignant disease to specialist palliative care services. The design of this study was a quantitative methodology and involved a postal questionnaire being forwarded to one hundred physicians working in hospitals in Wales. The physicians were working as general physicians and represented areas in geriatrics, rheumatology, neurology and other sub specialities of medicine. The response rate was 78%. Of those, 94% stated that they would consider referring patients with non-malignant disease to palliative care services. Whilst patients with chest disease are mentioned, the researcher was unable to identify if patients with Cystic Fibrosis were part of this. The sample of chest physicians surveyed was one of the smallest in the group of clinicians questioned (n=6). The results of this study demonstrate that there was a
positive feeling towards palliative care being available to patients and demonstrated support for a shared care approach. This was viewed as being a way of addressing the concerns of general physicians regarding the lack of disease specific knowledge within palliative care teams and would lead to a more integrated approach to care.

Interestingly in the same study physicians working with both stroke and dementia were less likely to refer to palliative care. The rationale for this related to either the long prognosis of these patients or that these conditions are without symptoms, despite previous evidence that has suggested this (Addington-Hall et al. 1998). A further interesting point is that this research explored what the actual concerns of physicians would be in referring to palliative care services. The most reported concern related to what patients would think about being referred to palliative care. Further concerns included a difficulty defining when end of life care begins, that doctors would become de skilled in delivering palliative care, and a concern that patients would feel abandoned by the primary treating team. Patients’ perceptions were not included in this study. Although this study did not mention Cystic Fibrosis it is helpful in identifying what clinicians feel about palliative care being involved in patient’s care. Shared care was highlighted as being the way forward for patients with non-malignant diseases but there was no guidance on how this could be achieved. The respondents described the difficulty in identifying end of life care in their groups of patients which may reflect clinicians’ perceptions of palliative care as an end of life care service.
Within the literature relating to non-malignant disease and palliative care Cystic Fibrosis is rarely mentioned. In 2001 a specific book relating to palliative care and non-cancer patients was published. Within this book Cystic Fibrosis was discussed over just two sentences (Addington-Hall & Higginson 2001). This may indicate the original lack of identified need in this speciality or perhaps may signify the complexities surrounding Cystic Fibrosis, because of the need for acute and palliative treatments running concurrently.

A study in 2009 offered questionnaires to 210 respiratory physicians exploring access to palliative care services for those patients with life limiting lung disease other than cancer. Patients with Chronic Obstructive Pulmonary Disease, Cystic Fibrosis, Asbestos disease and Diffuse Parenchymal Disease did not have equitable access to palliative care services compared to those with a lung cancer diagnosis, thus demonstrating the inequality of access to palliative care services (Partridge et al. 2009). Patients with Cystic Fibrosis accounted for approximately one third of the patient group. It was also acknowledged that in the majority of respondents (87.9%) there was no formal process in the hospitals for identifying patients at end of life. In only 20% of responses was there recognition that practice would extend to those patients with non-cancer related lung issues. In terms of access to hospice and day care facilities only 23% reported easy access to these services. Of the 210 questionnaires distributed a 51% response rate was achieved (n=107) (Partridge et al. 2009). This article again suggested that limited access at the end of life for patients with Cystic Fibrosis is likely to indicate limited access to palliative care early in the patient’s disease.
The contribution that palliative care services can make towards the control of patient symptoms has been recognised within the literature (Edmonds et al. 1998; Klepstad et al. 2005; Doyle et al. 2011). A study by Potter et al. (2003) identified, through a retrospective case note review, symptoms experienced by 400 patients over three clinical sites. In this study it was acknowledged that 95% of referrals were patients with a cancer diagnosis with symptoms of pain, anorexia, constipation, weakness and breathlessness. The remaining 5% with a non-malignant diagnosis were not discussed in this paper. It is unclear why these patients were not included in the findings.

It was important to identify from the literature how non-malignant diseases and access to palliative care services are perceived. This was helpful in considering the development of the research questions. A qualitative study in 2004 by Bestall et al. interviewed patients and professionals. This study focused on patients in the community and reported five key themes. These included reasons why patients are referred to palliative care, reasons why patients are not referred to palliative care, timeliness of referrals, and continuity of care and the use of referral criteria. This research highlighted that a lack of standardised triggers for referral to specialist palliative care was a limiting factor in the referral process. In this study the disease of the patient was not disclosed therefore the researcher was unable to determine if patients with cancer or non-malignant disease were interviewed.

From a hospital perspective a study was conducted using methods of focus groups and interviews with doctors and nurses (Ewing et al. 2009). The aim
was to describe user and provider perspectives on delivering a specialist service in the hospital. This research identified that there was agreement between users and providers of the service that hospital palliative care teams should be providing expertise in managing difficult symptoms and complex psycho-social issues. There was, however, disagreement with respect to what ward staff may be able to offer and when specialist palliative care should become involved. Specialist palliative care teams were concerned that they would be asked to provide generalist palliative care in areas of care neglected by ward staff such as ‘basic psychological care’. The authors did not disclose if ward staff were competent and educated in the provision of palliative care.

The views of patients were identified by McIlfatrick (2006). Patients were recruited from the general practitioner with diseases of the circulatory, respiratory or nervous systems. This study involved a mixed methods approach that incorporated semi structured interviews with patients and lay carers receiving palliative care services. Focus Groups were also conducted with health care professionals. The results of this study demonstrated that all participants recognised that there was inequity between palliative care service provision for patients with cancer and those with non-malignant disease. The patients that were selected for this study were from a range of different non-malignant diseases but only one had respiratory issues related to pulmonary fibrosis. No patients with Cystic Fibrosis were included in this study.
3.5. Barriers of Referral to Palliative care in Non-Malignant Disease

There are several possible reasons for variability in the pattern of referral to palliative care. These reasons include different patient needs, variability in the referrer and possible perceptions of patients towards a palliative care referral and ongoing care (O’Leary 2008; Broom et al. 2013).

In a quantitative study, a survey forwarded to palliative care managers demonstrated that specialist palliative care services were limited for patients with non-malignant disease in some way (O’Leary 2008). The number of patients seen with a non-malignant disease at that time accounted for only 7.2% of all referrals. In this study the top three barriers to referral of patients with a non-malignant disease included the unclear disease trajectory of other diseases, the difficulty in determining referral criteria and the lack of non-malignant expertise of specialist palliative care. This study had a 100% response rate to the questionnaire but was conducted in Ireland only.

In a similar way education and knowledge were also raised in heart disease where it was identified that barriers of referral to palliative care services included a limited knowledge of the heart failure specialists about palliative care and misperceptions (Kavalieratos et al. 2014). Difficulties in a lack of referral guidelines between heart failure and specialist palliative care were also identified. In this study the authors interviewed eighteen professionals to ascertain their perceived needs of patients with heart failure. Knowledge, attitudes and experiences of palliative care including timing of referral and what, perceived barriers were to referral to palliative care were generated as
concerns. However this study is limited because it focused on the perspectives of professionals only and did not ask patients what they would want from a specialist palliative care service. It was also limited in being representative of one area of the country only.

Broom (2013) interviewed twenty medical professionals from general medicine and surgery. When asked about how they introduce palliative care the authors concluded that professional responses were mediated by the specialists’ individual desires, subjective experiences and emotional characteristics. Each one had individual reasons regarding when and how they introduced palliative care.

A further study interviewed community professionals to explore influencing factors of referring patients with non-malignant disease to specialist palliative care (Andrews & Seymour 2011). The results from nine interviews indicated that perception of palliative care involved an association with services for dying patients. Although this study occurred in the community it is important to consider this as patients with Cystic Fibrosis are often not referred to community palliative care services, therefore being aware of the views of the community teams are important in considering how services can be integrated in future developments.

In 2014, Beernaert et al. conducted a qualitative study looking at identification of palliative care needs and potential barriers and facilitators of referrals to specialist palliative care. Focus groups were held with General Practitioners
(GPs) and community nurses. Eighteen interviews were conducted with patients. These patients were diagnosed with cancer, chronic obstructive airways disease, heart disease or dementia; no patients with Cystic Fibrosis were included. The perceived barrier in this study was patients’ perceptions of what to discuss with the family practitioner as they did not see them for anything other than acute care. The opportunity to build relationships with professionals was highlighted by the patients as being important.

A systematic review demonstrated concerns in accessing specialist palliative care services (Ahmed et al. 2004). Out of 9921 articles identified, 40 met the inclusion criteria. From this it was established that several barriers resulted in problems in accessing palliative care. These included lack of knowledge about specialist palliative care and that standardised referral criteria needed to be developed. It was also recognised within this review that some patient groups did not receive a timey referral to palliative care; this was inclusive of patients with non-malignant disease.

From a professional perspective a lack of knowledge or skill may trigger a referral or alternatively may prevent a referral from occurring to palliative care (Bestall et al. 2002; Bradley et al. 2002; Aitken 2006). In earlier studies education and training were observed as facilitating referrals to palliative care services (Friedman et al. 2002; Schim et al. 2000). Therefore understanding what patients with Cystic Fibrosis think about palliative care and those caring for them will be instrumental in developing new models of care.
In a retrospective review looking at predictors of access to a palliative care service it was identified that 499 out of 1453 (34%) patients had access to palliative care services. It was recognised that palliative care services can help in supporting those patients who have physical and psychological distress but as with other research it was highlighted that referral patterns should be more clearly defined. This review did not suggest what these should be (Fadul et al. 2007).

Other areas of non-malignant disease have acknowledged perceived barriers in referring to palliative care and have tried to identify ways of overcoming these (Gelfman et al. 2014). Whilst this article refers to heart failure some of the issues raised could be considered in the Cystic Fibrosis population. The authors identified that the lack of integrated care may be related to several factors. These factors include symptom control measures that involve active management such as intravenous antibiotics and it is stated that palliative care clinicians may not fully appreciate the benefits of such treatments. The authors also recognise the need for early palliative care to be considered but actually when this should happen is unclear. The timing of referral to palliative care and perceptions of clinicians both using and providing the service needs to be further explored.

Hayle et al. in 2003 investigated the experiences of 8 patients receiving specialist palliative care. Patients were recruited from chronic obstructive airways disease and had to have been known to a palliative care service for at least one month if the patient was an out-patient, or one week if the patient
was an in-patient. The results demonstrated that patients felt the benefits of access to this service including reduced frequency of hospital admissions with improved physical and psychological symptoms. Patients acknowledged how discussions about palliative care caused distress which related to the historical perspective of palliative care and the association with death and dying. Interestingly over time patients' views of palliative care changed and the patients associated palliative care with social inclusion. In searching the literature there was no such study for patients with Cystic Fibrosis.

It is recognised that perceptions about palliative care can cause confusion and lead to misperceptions about the service. A study in 2010 by Melvin explored misperceptions of palliative care and interviewed patients and families. In this study thirteen patients were interviewed (one withdrew) and six family members. It is not clear from this research what the patients' diagnoses were therefore the researcher was unable to determine if the patients had cancer or a non-malignant disease. The results of this study illustrated that patients had either no knowledge of palliative care or perceived that palliative care was a service that you had access to in the last 48-72 hours of life. The perception of palliative care being linked to end of life is not new and has been discussed in several other studies (Mitchell et al. 2000; Lowton 2009).

3.6. Patient and Professional perceptions of Palliative care in Cystic Fibrosis.

One article was identified relating to end of life care and this was reviewed in an attempt to try and determine views of the patients with Cystic Fibrosis.
relating to any perception of palliative care (Braithwaite et al. 2011). In this qualitative study a combination of focus groups and interviews was used to explore experiences of patients, families and staff on end of life care. The results highlighted areas regarding lack of knowledge for the patients relating to palliative care. Actual perceptions of palliative care were not addressed in this article from a patient perspective. Although this article related to end of life care it did identify that knowledge of palliative care for patients' required further exploration.

Interestingly a qualitative study researched public awareness of perceptions of palliative care (Mcllfatrick et al. 2014). This study was on the basis of an understanding that the public were confused regarding the meaning of palliative care. This study involved telephone interviews with 50 members of the public. The results from this study illustrated that the public's knowledge of palliative care is determined by their own personal experiences. They indicated that palliative care related to care of people who were dying and maintaining comfort. There was no mention of access to palliative care earlier in the patient’s disease trajectory.

There were no articles retrieved that had researched professionals working in Cystic Fibrosis and their perception of palliative care. The researcher did however look at a sample of articles to assess other professional perceptions of palliative care. In 2007 Pavlish & Ceronsky invited oncology nurses to be part of Focus Groups to explore their perceptions of palliative care. In total 33 nurses participated in the study. The study concluded that the oncology nurse
understood the goals of palliative care however they recognised that the nurses considered palliative care being synonymous with end of life care.

A further qualitative study (Davidson et al. 2003) explored perceptions of palliative care with cardio-respiratory nurses. This study involved 35 nurses and six focus groups participating in Focus Groups the results from which determined that some of the nurses felt that palliative care was only for cancer and dying patients. They also referred to the challenge of acute and palliative care being offered simultaneously.

3.7. Integrated Care between Palliative Care and Cystic Fibrosis

The literature referred to the fact that people who live with complex care needs receive health and social care services from multiple providers. This occurs across different care settings and suggests that with a more coordinated care system better planning of more cost-effective services will ensue to facilitate a more individualised service for the user with timely access to appropriate information (Shaw et al. 2011). In enabling integrated care it is hoped that barriers to services can be identified and where possible, solutions developed that currently prevent integrated working.

It has been indicated that palliative care requires a different model of care due to an increasing demand for the service and concern over the number of current providers (Quill & Abernethy 2013). This article recognised that whilst patients should be assessed by a palliative care specialist the patient’s care
should be returned to the primary clinician when indicated by the clinicians involved. In this way there would be an increased availability of palliative care services to a wider population.

Only one article retrieved addressed an integrated model of care between Cystic Fibrosis and palliative care (Bourke et al. 2009). This article’s title refers to an integrated model of palliative care to patients with Cystic Fibrosis. The retrospective review reported on 40 patients with Cystic Fibrosis who were referred to as terminal patients. Whilst the introduction to the article is suggestive of an integrated model in palliative care on further reading it clearly relates to end of life care. The article suggested a way of palliative care supporting the Cystic Fibrosis team to deliver palliative care which actually referred to end of life care. This study did not discuss the relationships of palliative care with patients or if any of the patients had been reviewed by palliative care earlier in the patient’s disease trajectory. The study indicated palliative care being involved when needed but as acknowledged in a previous study (Lowton 2009), families do not want palliative care being introduced towards the end of the patient’s life. The significance of this being that involving palliative care earlier in Cystic Fibrosis has not been researched.

3.8. Summary

In concluding this chapter the researcher has identified that there is a gap in the literature relating to palliative care and Cystic Fibrosis. Studies reviewed focused predominantly on end of life care. In undertaking the literature review, when the term palliative care was entered into the search engines, the articles generated identified end of life care literature suggesting the association of
palliative care with death and dying. There were no studies identified that offered perceptions of patients with Cystic Fibrosis towards palliative care. The literature has highlighted that patients with non-malignant disease have similar symptom control needs to those with cancer and that there is an apparent inequity of access to palliative care for patients with Cystic Fibrosis.

Interestingly when palliative care was alluded to in the literature there was no discussion of how or when that actual referral would take place. This was highlighted in one of the qualitative articles when a mother commented on a palliative care nurse coming two hours before the death of her adult child (Lowton 2009). Clinicians recognised their hesitancy in referring to palliative care in case of causing upset to patients, however in patients with Cystic Fibrosis their views have not yet been explored. Access to palliative care services was not discussed in any of the articles relating to symptom control in patients with Cystic Fibrosis.

In both qualitative and quantitative studies relating to non-malignant disease and palliative care, patients with Cystic Fibrosis were invariably not included within the sample of participants; however not all studies declared the diagnosis of the patients. Within the literature the focus of palliative care in Cystic Fibrosis equates with end of life care and there were no studies looking at early palliative care for patients with Cystic Fibrosis. It is also indicated that health care professionals equate palliative care with death and dying. Whilst integrated working is alluded to in a limited number of articles there are no recommendations as to how this could evolve earlier in the patient’s disease
trajectory. The literature critiqued involved both qualitative and quantitative studies, there were limited numbers of mixed methods studies and none looking at early palliative care in patients with Cystic Fibrosis. The majority of methods used involved focus groups and interviews. The literature relates to sensitive topics of palliative care, end of life care and bereavement therefore the use of interviews and focus groups are appropriate. The focus of the studies relate to end of life care and whilst issues such as symptom control and inequity of services are indicated there are limited solutions offered to support the development of future services.

The literature review highlighted gaps in the following areas:

1. Although study titles included palliative care, the studies actually related to end of life care
2. There were no studies identified where early palliative care had been explored in patients with Cystic Fibrosis or health care professionals caring for patients with Cystic Fibrosis.
3. There was a limited number of research articles offering an integrated model of care between Cystic Fibrosis and palliative care.
4. There was a limited number of mixed methods studies used and none exploring early palliative care in patients with Cystic Fibrosis.

Palliative care as a service is one which should be available to patients at all stages of their disease trajectory (WHO 2002). The literature review has highlighted barriers to such referrals in specialities of cancer and other non-malignant conditions. It is evident that patients with Cystic Fibrosis are living
longer but this is with a significant symptom burden for which there is some perception was that these symptoms could not be controlled (Stenekes et al. 2009; Keleman et al. 2011; Havermans et al. 2013). The role of palliative care reviewing this group of patients early in their disease trajectory for symptom control has not been explored. Exploring what both patients with Cystic Fibrosis and health care professionals caring for them understand about palliative care will help in determining when it would be a good time to introduce palliative care services, resulting in the potential to develop new models of integrated working between the two specialities. As a result of the literature review, research questions have been developed with an overall aim and are illustrated in Table 5.

**Table 5. Research Aim and Questions**

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<th>Research Aim</th>
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<td><strong>Research Aim</strong></td>
<td>1. To explore the experiences and perceptions of patients with Cystic Fibrosis and staff regarding palliative care and the acceptability of this as a service early in the patient’s disease trajectory.</td>
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| **Research Questions** | 1. What are patients with Cystic Fibrosis and health care professionals’ experiences and perceptions of palliative care?  
2. What are the barriers and facilitators of a palliative care referral in Cystic Fibrosis?  
3. Are the services for the provision of palliative care within Cystic Fibrosis integrated as part of a multi-disciplinary team? |
CHAPTER 4: RESEARCH METHODOLOGY

4.1. Introduction

This chapter will begin by considering the purpose of this study and will discuss the research design used. In undertaking a literature review the need for this study was defined and in order to answer the research questions a mixed methods study has been adopted. The following chapter will address the understanding of qualitative and quantitative research, and will reflect on the researcher’s epistemological standing. Within this section, a rationale will be given behind the choice of a mixed methods study and clarify the type of mixed methods study used. The following chapter will also explore the concept of integrated care, the underpinning theoretical framework for the current study. The chapter will close with a summary of the preceding discussion.

4.2. The Epistemological Position of the Researcher.

It is suggested that before any research can take place the researcher should consider their own philosophical beliefs about how they see the world (Packford & Polifroni 1992). In previous accounts Parahoo (1997) recognised that nurses have beliefs and values that are consistent with a qualitative paradigm and that this is the chosen method of many nursing studies. In taking this further Paley (2001) proposed two reasons for this, either nurses have acquired the assumptions associated with the qualitative paradigm through professional socialisation or, he believes, they have a temperament
that attracted them into a profession where caring is paramount and suggests that this sits easier with a qualitative paradigm.

The researcher reflected on her own philosophical and ontological perspectives and it became clear that she sits within the constructivism paradigm as she believes that human beings construct their social reality where participants and researchers will construct meaning together (Holloway & Wheeler 2010). It is clear from reflections that the paradigm of constructivism, whereby individuals construct their own reality resulting in their being multiple interpretations, sits comfortably with the researcher (Glaser 2002). In considering the development of the research questions it was necessary to address the most appropriate way to answer them. Following discussions and further research into other methodologies the researcher decided the use of mixed methods was the only way to address the research questions completely. This would entail considering both qualitative and quantitative paradigms. Figure 4 below illustrates a diagrammatic representation of the process in developing the eventual research methodology. The actual process included consideration of the researcher’s clinical experience on the topic to be researched as well as the lack of evidence available in the literature proving that there was a gap in this area of research. Being aware of the researchers own beliefs, and values as well as discussion with research supervisors, was important in establishing the final methodology. Whilst the researcher does sit within a qualitative research paradigm it was clear that in order to answer the research questions, mixed methods would be the most appropriate methodology to use.
4.3. Position of the Researcher within the Study

The literature reminds us that researchers choose an area to research usually out of interest in the topic (Holloway & Wheeler 2010). In this study the researcher became interested in the integration between palliative care and patients with Cystic Fibrosis as a result of being clinically exposed to this area. It is important at the beginning of the research to be transparent about pre-existing assumptions regarding the topic to be studied. The researcher recognised that her experience spanned more than twenty-five years in palliative care and with that came views on palliative care both personal and professional. The researcher has a passion for palliative care but also acknowledged that she had limited knowledge of palliative care and Cystic Fibrosis. Clinical experience of the researcher helped her identify that the
referral process was not always predictable and thus, she considered this warranted further investigation. The researcher was known to one of the research sites but was not delivering the clinical services or directly managing any members of staff. Existing assumptions were acknowledged through reflecting on the literature and after each part of the data collection. A copy of part of the reflection can be found in Appendix 1.

4.4. The Purpose of the Research

As a result of reconfiguration of specialist palliative care services in a tertiary referral cancer centre, the researcher was asked to be involved in the development of services at a local tertiary heart and lung hospital. In undertaking a clinical review of this group of patients as requested by the Cystic Fibrosis team it became apparent that patients with Cystic Fibrosis had palliative care needs but that the palliative care service was called in only at the end of the patient’s life, if at all. Based on this clinical experience the researcher became intrigued with what appeared to be a palliative care service that delivered end of life care on an as required basis only. As discussed in Chapter 3 a critique of the existing literature highlighted areas for further research in palliative care and Cystic Fibrosis.

4.5. An Overview of Quantitative and Qualitative Paradigms and the Position of Mixed Methods Research

Research methodology defines the way in which a research project is to be undertaken. It also establishes the methods to be used within such
methodology (Neuman 2009). In developing the methodology it was important for the researcher to consider the research questions and the advantages and disadvantages of both qualitative and quantitative research. A useful table of advantages and limitations of qualitative and quantitative research can be viewed in Table 6 below.

Table 6. Advantages and Limitations of Qualitative and Quantitative Research (Creswell 2014 pp.5).

<table>
<thead>
<tr>
<th></th>
<th>Qualitative research</th>
<th>Quantitative Research</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Advantages</strong></td>
<td>Provides detailed perspectives of a few people</td>
<td>Draws conclusions from large numbers of people</td>
</tr>
<tr>
<td></td>
<td>Captures the voice of participants</td>
<td>Analyse data efficiently</td>
</tr>
<tr>
<td></td>
<td>Allows participants’ experiences to be understood in context</td>
<td>Investigates relationships within data</td>
</tr>
<tr>
<td></td>
<td>Is based on the views of the participants not of the researcher</td>
<td>Examines probable causes and effects</td>
</tr>
<tr>
<td></td>
<td>Appeals to people’s enjoyment of stories</td>
<td>Controls bias</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Appeals to people’s preference for numbers</td>
</tr>
<tr>
<td><strong>Disadvantages</strong></td>
<td>Has limited generalisability</td>
<td>It is impersonal, dry</td>
</tr>
<tr>
<td></td>
<td>Provides only soft data (not hard data such as numbers)</td>
<td>Does not record the words of participants</td>
</tr>
<tr>
<td></td>
<td>Studies few people</td>
<td>Provides limited understanding of the context of the participants</td>
</tr>
<tr>
<td></td>
<td>Is highly subjective</td>
<td>Is largely researcher driven</td>
</tr>
<tr>
<td></td>
<td>Minimise use of researcher’s expertise due to reliance on participants</td>
<td></td>
</tr>
</tbody>
</table>
Starting from the 19th century the traditional approach to social and behavioural research was quantitative which had its routes in the positivist and early natural science model (Holloway & Wheeler 2010). Positivism was described as “an” approach to science based on a belief that attempts to present an objective picture of the world” (Paley 2001). It is also considered that this research has a quest for objectivity and suggests that distance between the researcher and those being studied can be avoided. In contrast qualitative research is described as a form of social inquiry that focuses on the ways in which people make sense of their experiences and the world in which they live (Neuman 2009).

Researchers use this methodology to explore behaviour and feelings and experiences of people. It is suggested that the basis of this approach sits in the interpretive approach to social reality and in the lived experiences of human beings (Holloway & Wheeler 2010). Mixed methods research has been referred to as the third methodological movement following first quantitative research and then qualitative research (Creswell & Plano Clark 2011). Health care managers are placing greater emphasis on clinicians being able to prove their impact on the delivery of the care they provide (Gaziano et al. 2007). Mixed methods research has been recognised as being able to meet the needs of health care professionals in undertaking this complex research (Andrew & Halcomb 2009).
4.6. Mixed Methods Research

A mixed methods study was selected to investigate early palliative care in the adult Cystic Fibrosis population. Mixed methods studies have been defined as: combining qualitative and quantitative approaches into the research methodology of a single study or multi-phased study, and integrates or connects data at some point of the research process (Andrew & Halcomb 2009; Tashakkori & Teddlie 2010). The use of both qualitative and quantitative design can be useful to both answering the research question and minimising research bias as well as enhancing the validity of the results by testing the consistency of findings obtained by different methods (Bowling 2009). It has also been advocated that the nature of investigating complex health care issues can benefit from a more flexible mixed methods approach (O’Cathain et al. 2007; Bowling 2009; Holloway & Wheeler 2010). Mixed methods are defined as an approach in which the researcher collects, analyses, and integrates both quantitative and qualitative data in a single study or in multiple studies in a sustained programme of inquiry. Thus mixed methodology sits well within the multi-phase model of complex intervention development and evaluation. This is particularly important for the researcher in considering the sensitivity of the subject to be researched and the issue of Patients with Cystic Fibrosis being a relatively small group living with a chronic complex life limiting illness diagnosed primarily from birth.

The idea of mixing qualitative and quantitative methods has stimulated much interest and debate. The concept of mixing data has been used for approximately forty years (Andrew & Halcomb 2009). Researchers
increasingly have used mixed methods to expand the scope of, and deepen their understanding of particular topics. It is suggested that the complexity of human phenomena mandates more complex research designs to capture them and it is argued that a mixed methods methodology can address this issue (Swanson, 1992; Sandelowski, 1995; Greene & Caracelli, 1997; Creswell 2003; Fleming 2007; Tashakkori & Teddlie, 2010).

Mixed methods are particularly valuable in palliative care research, where the majority of interventions are complex, and the process of evaluation and identification of suitable outcomes is particularly challenging (Patterson et al. 2009; Cawley et al. 2011). Qualitative data will yield information about subjective experiences, understandings, effects and impacts, and can therefore augment quantitative data in hypothesis generation, defining interventions, questionnaire or instrument design (Farquar et al. 2011).

It is suggested that it is important to be clear about why a mixed method design is being used (Creswell & Plano Clark 2011). There are at least sixteen reasons why a researcher may consider applying a mixed method design and the literature acknowledges that often researchers are alluding a myriad of reasons as to why mixed methods are being used Bryman (2008). There are several reasons why on this occasion a mixed methods design is being used. The reasons can be viewed in Table 7.

The research questions in this study will be best answered using a mixed methods methodology. This will allow the researcher to not only understand the perceptions of patients and professionals about palliative care but will also
allow the researcher to better understand how care is currently delivered between palliative care and Cystic Fibrosis services nationally.

Table 7. Reasons for selecting Mixed Methods (Bryman 2008)

<table>
<thead>
<tr>
<th>Reason</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completeness</td>
<td>The researcher can bring together a more comprehensive account of the area of inquiry</td>
</tr>
<tr>
<td>Instrument development</td>
<td>Refers to the context in which qualitative research is employed to develop questionnaires</td>
</tr>
<tr>
<td>Credibility</td>
<td>Employing both approaches enhances the integrity of the findings</td>
</tr>
</tbody>
</table>

4.7. The Research Design

Researchers are advised that there are several key questions that must be considered before deciding on a mixed methods study (Creswell 2003). They include in what sequence will the qualitative and quantitative data collection be implemented, secondly what relative priority will be given to the data collection and analysis, at what stage of the research will the data be integrated. Each of these questions will now be considered to demonstrate transparency to the choice of the research method.

The evidence regarding mixed methods suggests that both qualitative and quantitative data can be collected either sequentially or simultaneously (Andrew & Halcomb 2009; Creswell & Plano Clark 2011). The sequence should be informed by the research questions to be answered. The researcher identified that the data in this study would be collected sequentially in order to answer the research questions.
The literature suggests determining the priority of the quantitative and qualitative strands of the research (Creswell & Plano Clark 2011). There are three possible options for a mixed methods study. The options are either to treat the different strands equally or for the study to use a quantitative priority or a qualitative priority. For the purposes of this research each strand has equal priority as all strands contribute to answering the research questions.

Integration of the data can occur at various stages of the research process, either during data collection, data analysis and/or interpretation of the data (Andrew & Halcomb 2009). There are several points when mixing of the different strands can occur. In this research project the mixing of the methods occurred through the data collection period. This is referred to as using a strategy of connecting where the results of one strand of the research builds to the collection of the next form of data (Cresswell & Clark 2011). The so-called connection occurs by using the results from the first strand to form the collection data in the second strand and subsequently for the third strand (Cresswell & Clark). This is done to specify research questions, select participants or to develop data collection tools (Creswell & Plano Clark 2011). The type of design used in the study is described as an exploratory sequential design.

4.7.1. Introduction to the Qualitative and Quantitative Methods
The qualitative arm of the study was guided by the principles of Grounded Theory analysis using one Focus Group in Phase 1 and semi-structured one to one interviews in phase 3. The quantitative data were collected following a
short survey of twenty one questions in Phase 2. The following table adapted from Crotty (1998) demonstrates the research methods for each phase. These will be discussed further in the methods section.

Table 8. Research Methods (Adapted from Crotty 1998)

<table>
<thead>
<tr>
<th>Methodology</th>
<th>Methods</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Qualitative</td>
<td>Principles of Grounded Theory</td>
<td>Phase 1 Focus Group Phase 3 One to one semi structured interviews</td>
</tr>
<tr>
<td>Quantitative</td>
<td>Survey Research</td>
<td>Phase 2 Questionnaires emailed directly to leads for palliative care and Cystic Fibrosis (n=46)</td>
</tr>
</tbody>
</table>

4.7.2. Grounded Theory Approach

The principles of a constructivist Grounded Theory approach have been applied to analyse the qualitative data generated from this study. First developed by Glaser & Strauss in 1967, this theoretical approach was situated towards an objective perspective that is affiliated more towards positivist traditions. Over the years the methodology has been developed and constructivist Grounded Theory espoused by Charmaz (2014), more recently underpins the epistemological paradigm of Phase 1 and 3 of this study. Grounded Theory has been recognised as focusing on the development of theory from the ground up as well as identifying that Grounded Theory methods are of particular significance within a mixed method research design (Birks & Mills 2011). The place of Grounded Theory is recognised within
mixed methods research as an approach to ensure rigorous management of qualitative elements of the research (Cagle & Wells 2008; Birks & Mills 2011).

Grounded Theory is referred to in the literature in the late 1960’s following the publication of research relating to death and dying by Glaser & Strauss (1967). Glaser was recognised as having a strong quantitative background as opposed to the qualitative background of Strauss. Following this research they proceeded to equip researchers with methodological strategies that could be adapted to further research in other areas as well as proposing that systematic qualitative analysis had its own reasoning and could create theory (Charmaz 2014). The literature also recognised that theorists of Grounded Theory who come from a different view point all begin with inductive logic and subject the data to rigorous comparative analysis and to develop theoretical analysis that will inform future practice (Charmaz 2014).

The Grounded Theory method seeks through focus groups and interviews to discover concepts and to construct theories originating from the data. Authors have suggested that generating a theory about a topic is effective when there is little known about a subject (Crotty 1998; Denzin & Lincoln 2000). Whilst there is much known about the construct of palliative care there is little known about Cystic Fibrosis and palliative care regarding the views and perceptions of patients and staff earlier in the patient’s disease trajectory.

Constructivist is the term used to acknowledge the subjectivity and the researcher's involvement in the construction and interpretation of data.
gathered (Charmaz 2014). If researchers believe that social reality is constructed then the researcher’s position perspectives and interactions should be taken in to account (Charmaz 2014). It is also suggested that this approach does not aim to recognise truth but does identify the true reality or views of the participants’ experience (Charmaz 2014). This perspective of Charmaz (2014) recognises that the main issue is in the identification and analysis of data through the relationship with the participants and through the shared experience. The researcher recognised existing paradigms related to Grounded Theory (Glaser & Strauss 1967; Strauss & Corbin 1990 & Charmaz 2000) but identified that the constructivist approach was the one best suited to the research and the epistemological stance of the researcher.

In Grounded Theory the data collection and analysis occurs simultaneously; a process that the researcher adhered to in this study. Initially the sampling was taken from a purposive sample and subsequently transitioned to theoretical sampling based on the clues the researcher gained from the data being generated (Birks & Mills 2011).

4.7.3. Criteria for Rigour in the Qualitative Phase

In qualitative research the term trustworthiness is more often referred to than validity and reliability (Holloway & Wheeler 2010). Researchers make judgements of trustworthiness possible through developing dependability, credibility, transferability and confirmability. It is proposed that of these, credibility is the most important (Guba & Lincoln 1985). In this study rigour was achieved through the following:
**Dependability:** findings from the study should be consistent and accurate and readers should be able evaluate the analysis through following the decision making process of the researcher as well as having a clear audit trail demonstrating how conclusions were reached. Each phase of this study was described in detail and the development of categories were discussed with peers and supervisors. A clear plan of the study is available in Figure 5, Chapter 4.

**Credibility:** relates to the findings being compatible with the perceptions of the people being studied. The experience of the researcher within the field, peer examination and reflexivity are all considered within credibility. The researcher had over twenty-five years experience in the field of palliative care and throughout the study used a reflective journal. The interviews and the focus group findings were discussed at length with supervisors and results from the data were discussed at research meetings with peers and at regular meetings with supervisors.

**Transferability:** relates to the findings in one context being transferred to similar situations or participants. The ability to transfer concepts from this study could be helpful in applying to other patients with non-malignant conditions where the evidence for early palliative care is under researched.

**Confirmability:** the researcher is judged by the way in which the findings and conclusions achieve their aim and are not the result of the researcher’s prior assumptions. This was achieved through a clear decision trail relating to the
development of themes and categories previously discussed with peers and supervisors. Extracts from the researcher's reflective journal were discussed at monthly supervision sessions and an extract is available in Appendix 1.

**4.7.4. The Quantitative Method**

The following definition, taken from Aliaga & Gunderson (2002), describes quantitative research methods as explaining occurrences by collecting numerical data that are analysed using mathematically based methods. In order to answer the research questions it was important to try and establish what the national picture was for completeness of the study in terms of referral processes between the two services and perceptions of such referrals.

Surveys are used to measure certain topics and to look at the behaviour and attitudes of the population of interest (Bowling 2009). This type of survey is referred to as a descriptive survey and descriptive measures will be calculated (Bowling 2009). This type of survey is also referred to as a cross sectional survey because the data are collected from the population at one point in time.

The need to ensure that the questions for the survey were not based on assumptions of the researcher is an important factor in the construction of the questionnaire (De Vaus 2002). The questions for the survey were based on findings raised by experts in both Cystic Fibrosis and palliative care from the focus group in Phase 1. The development of the questionnaire and the conduct of using the survey are described in the methods section.
4.7.5. Decisions for Analysing and Interpreting Data in Mixed Methods Research

In the exploratory sequential design the data analysis is clearer as the qualitative and quantitative elements are analysed in different phases and are not merged (Creswell & Plano Clark 2011). The use of a data analysis procedure can help in the process of ensuring rigorous data analysis procedures for both quantitative and qualitative analysis. Table 9 illustrates the mixed methods data analysis applied and the areas in bold illustrate the process taken within this study.

Interpreting connected results can also be referred to as drawing conclusions or drawing inferences (Creswell & Plano Clark 2011). Although inferences can be described after each phase of the research the meta-inferences should be concluded later in the study. For the researcher in considering the exploratory sequential design the meta-inferences relate to whether the additional strands of the study provide a more generalized understanding of the problem rather than using a single data set alone (Creswell & Plano Clark 2009). This will be further discussed in Chapter 6 in the data analysis.
Table 9. Mixed Method Data Analysis (Adapted from Creswell & Plano Clark 2011).

<table>
<thead>
<tr>
<th>Type of design Decision</th>
<th>Type of data analysis</th>
<th>Data analysis steps taken in Study</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Exploratory</td>
<td>Connected data: each phase informed the next phase</td>
<td>1. Collect the qualitative data 2. Analyse the data using the most appropriate method <strong>Based on the principles of Grounded Theory</strong> 3 Design the quantitative phase based on results <strong>Questionnaire tool developed</strong> 4 Collect the quantitative data <strong>Questionnaire approved by ethics and forwarded to specialist teams in research centres</strong> 5 Analyse the quantitative data based on the most appropriate approach <strong>SPSS Version 21 used descriptive statistics generated</strong> 6. Develop the interview topic guide <strong>Interview topic guide developed</strong> 7. Conduct the interviews <strong>17 interviews conducted</strong> 8. Analyse the interviews <strong>Interviews analysed using the principles of Grounded Theory</strong> 9. Interpret how the connected results answer the research questions <strong>Interpretation of results</strong></td>
<td>Decide what data can inform the quantitative phase Decide how the qualitative and quantitative results build or expand on the findings</td>
</tr>
</tbody>
</table>
4.7.6. Validity in Mixed Methods Research

The term validity in mixed methods research is viewed as one of the most important issues in the research project (Creswell & Plano Clark 2011). Validity is frequently related to the design and the interpretation stage of the design. Onwuegbuzie & Johnson (2006) discuss issues of validity preferring to label it legitimisation when they refer to the design, the data analysis and interpretation of the study. It is suggested that validity relates to employing strategies that address potential issues in data collection, analysis and interpretation that might compromise the connecting of the data and the conclusions drawn from this (Creswell & Plano Clark 2011). The researcher considered the issues they attribute to potential issues of connecting data.

The following table describes the issues of validity as suggested by Creswell & Plano Clark (2011). The table below (Table 10) includes the way in which threats to validity were minimised in this study based on these principles. The column on the right hand side of this table has text written in bold to demonstrate ways in which the threat to validity was minimised.

Figure 5 illustrates the actual final research design of the study and how each phase and method applied would answer the research questions.
Table 10. Strategies for minimising threat to Validity (Creswell & Plano Clark 2011)

<table>
<thead>
<tr>
<th>Potential Validity Threats Using Mixed Methods</th>
<th>Strategies for Minimising Threat</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Data Collection Issues</strong></td>
<td></td>
</tr>
<tr>
<td>Selecting inappropriate individuals for both qualitative and quantitative design</td>
<td>Select same individuals to follow up the findings. Use different individuals when building new components. Research: different appropriate individuals selected in each phase</td>
</tr>
<tr>
<td>Using inappropriate sample sizes</td>
<td>Larger size for the quantitative arm. Research: Sample size larger in the quantitative arm</td>
</tr>
<tr>
<td>Not designing an instrument with sound psychometric properties</td>
<td>Using appropriate procedures for validating the instrument. Research: Survey tool piloted by experts in developmental phase; approved by ethics</td>
</tr>
<tr>
<td><strong>Data Analysis Issues</strong></td>
<td></td>
</tr>
<tr>
<td>Choosing weak quantitative results to follow up with qualitative</td>
<td>Choose the issues that need further follow up. Research: each phase informed next i.e. Results from questionnaire informed semi structured interviews</td>
</tr>
<tr>
<td>Choosing weak qualitative findings to follow up on quantitatively</td>
<td>Use major themes for the qualitative follow up. Research: Main theme from focus group informed some of the questions of the survey</td>
</tr>
<tr>
<td>Including qualitative data in an intervention trial without a clear intent of its purpose</td>
<td>Specify how each form of the qualitative data be used in the study. Research: each phase of the data was placed to answer the research questions</td>
</tr>
<tr>
<td><strong>Interpretation Issues</strong></td>
<td></td>
</tr>
<tr>
<td>Comparing the 2 data sets when they are meant to build rather than merge</td>
<td>Interpret the data to answer the research questions. Research: each dataset interpreted separately</td>
</tr>
<tr>
<td>Interpreting the databases in reverse order</td>
<td>Order the interpretation to fit the design. Research: data interpreted as the research design stated</td>
</tr>
<tr>
<td>Not taking full advantage of the potential of before or after qualitative findings for an interventional trial</td>
<td>Consider the reasons for using qualitative data in an interventional trial. Research: Not Applicable</td>
</tr>
<tr>
<td>Not relating the stages or projects in a multiphase study to each other</td>
<td>Consider how a problem, a theory or a lens might be an overarching way to connect the stages or projects. Research: All stages built upon next phase of the study</td>
</tr>
<tr>
<td>Irreconcilable differences among different researchers on a team</td>
<td>Researchers on a team need to agree to the overall project objectives and to negotiate methodological differences. Research: Researcher and supervisors in agreement with study design</td>
</tr>
</tbody>
</table>
Figure 5. Diagrammatic representation of research

**Phase 1 (Developmental: Qualitative)**
- Ethics approval
- Focus group to identify domains and questions for survey questionnaire and will offer insight and answer part of research question 1
- Participants recruited from the 2 research sites participating in the study
- Development of questionnaire and Pilot study of questionnaire
- 23 UK Cystic Fibrosis centres contacted and respective Palliative care providers identified

**Phase 2 (Quantitative)**
- Survey forwarded to Cystic Fibrosis team and palliative care teams
- 1. Will help answer research questions
- 2. What are the barriers and facilitators to staff making a referral to Palliative care
- 3 How are services integrated between CF and PC?

**Phase 3 (Qualitative)**
- Interviews in specialist Cystic Fibrosis centre local, nurses, physiotherapists, doctors from both specialities (up to 8)
- Interviews in specialist Cystic Fibrosis centre outside London, nurses, physiotherapists, doctors from both specialities (up to 8)

*Will answer second part of question 1 regarding patient perception and experiences of palliative care Will also add in depth knowledge to question 2 regarding barriers and facilitators and question 3 in determining further how services are integrated between CF and PC, following which interpretation of the data will take place*
4.8. Summary

This chapter has stated the epistemological position of the researcher and explored the choice of a mixed methods study. The design of the study has been described and detailed information regarding validity and data analysis has been presented. The following section will address the methods used to collect the data in the three phases of the study.
CHAPTER 5: RESEARCH METHODS

5.1 Introduction

The methods to be discussed will include the focus group that was used to gather data in Phase 1, a survey in Phase 2 and semi-structured interviews that were used in phase 3. The rationale for the choice of methods was based on the methodology chosen and research questions. The aims of the study and research questions are illustrated in Table 11 below.

Table 11. Research Aim and Questions

<table>
<thead>
<tr>
<th>Research Aim</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. To explore the experiences and perceptions of patients with Cystic Fibrosis and staff regarding palliative care and the acceptability of this as a service early in the patient’s disease trajectory</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Research Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What are patients with Cystic Fibrosis and health care professionals’ experiences and perceptions of palliative care?</td>
</tr>
<tr>
<td>2. What are the barriers and facilitators of a palliative care referral in Cystic Fibrosis?</td>
</tr>
<tr>
<td>3. Are the services for the provision of palliative care within Cystic Fibrosis integrated as part of an multi-disciplinary team</td>
</tr>
</tbody>
</table>

The three phases of the study will be discussed separately to fully understand necessary considerations in each of the different areas. The chapter will conclude with an overview of ethical considerations throughout the study and a risk assessment. The chapter commences with illustrating the inclusion and exclusion criteria of the participants for the focus group, the survey and the interviews in Table 12 below.
**Table 12. Inclusion/Exclusion Criteria**

<table>
<thead>
<tr>
<th>Phase 1 Focus Group</th>
<th>Inclusion</th>
<th>Exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Experts in both Cystic Fibrosis and Palliative care. (working in senior positions within speciality and working in specialist centres, more than 12 months)</td>
<td>Professionals not working in senior positions within speciality</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Professionals not working in specialist centres</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Phase 2 Survey</th>
<th>All adult specialist Cystic Fibrosis teams listed on the Cystic Fibrosis website 2012 (Lead clinician identified)</th>
<th>Teams not listed on the Cystic Fibrosis website</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All hospital palliative care teams associated with Cystic Fibrosis teams identified on the Cystic Fibrosis website (Lead clinician identified)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Phase 3 Interviews</th>
<th>Adult patients with a confirmed diagnosis of Cystic Fibrosis at any stage of illness (aged 18 or over)</th>
<th>Patients who are deemed clinically too unwell to participate in an interview.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Patients who understand English</td>
<td>Any patient who lives more than 2 hours away from the research site</td>
</tr>
<tr>
<td></td>
<td>Patient has mental capacity to participate (assessed by the Cystic Fibrosis team)</td>
<td>Patient who does not understand English (no funding for interpreting service)</td>
</tr>
<tr>
<td></td>
<td>Any trained clinical member of staff involved in the care of a patient with Cystic Fibrosis /Palliative care working at the specialist centre who has:</td>
<td>Staff who have less than 12 months experience in the speciality</td>
</tr>
<tr>
<td></td>
<td>worked with Cystic Fibrosis/Palliative care patients for more than 12 months</td>
<td></td>
</tr>
<tr>
<td></td>
<td>who spend more than 20% of their working day caring for patients with Cystic Fibrosis</td>
<td></td>
</tr>
</tbody>
</table>
5.2. The Selection of Research Sites

Following a re-configuration between two specialist hospital Trusts an opportunity had arisen for the palliative care team to work closer with the Cystic Fibrosis team. The lead clinician of the Trust for Cystic Fibrosis was approached and agreed to that site being involved in the study. From clinical experience, and the literature, it appeared that current integration of services was not understood between Cystic Fibrosis and palliative care teams. Therefore it seemed appropriate to answer the research questions it would be necessary to secure a second site outside London to explore another service. From the list of specialist adult sites on the Cystic Fibrosis Trust website a second Trust was identified. The lead clinician was approached by the researcher. The suggested research project was presented at both sites and both agreed to be part of the study. Teams based in Scotland were excluded as the healthcare system is different and configuration and funding of services are not designed in the same way as in the English health care system.

5.3. The Rationale of a Focus Group as a Method of Data Collection

It is recognised that focus groups are group discussions that are conducted to review a particular subject and that they are useful in examining what people think, their views and beliefs about a particular topic (Kitzinger 2005). The focus group is also an effective way of determining why different groups think of things in a different way. As the two groups of Cystic Fibrosis and palliative care were coming together to discuss a sensitive topic, a focus group seemed the most appropriate method to gain understanding into this subject area.
There was no validated questionnaire to use for the survey in phase 2 therefore the use of focus group with experts from both Cystic Fibrosis and palliative care was the best way to understand perceptions and thoughts regarding palliative care. The results from this would inform the questions to be asked in phase 2. Previous research has recognised the use of focus groups as being particularly effective in survey item development (Nasser-McMillan & Borders 2002). Although the research aim of this study was not to address death and dying, the nature of the life limiting aspects of Cystic Fibrosis and the known links from the literature between palliative care and an association with death and dying meant that consideration of potential upset of the professionals was important to be aware of. The researcher ensured additional support from the staff support department was made available to participants if needed.

5.4. Phase 1: The Focus Group

The study was approved by the local research committees of both research sites with ethical approval from South East Surrey Coast and the University of Surrey Ethics Committees (Appendices 2 and 3). Following this approval, the focus group was planned. Due to financial and time constraints a decision was made to invite experts from both Trusts involved in the study to take part in the focus group. Prior to starting any of the data collection the researcher met with both respective teams to inform them that the data collection phase was due to start.
As addressed in the literature in planning the focus group consideration was given to recruitment and gaining access to potential research participants, funding issues with respect to travelling expenses, the location and venue, the use of a field note taker and practicalities such as the securing of tape recording equipment (Liamputtong 2011). The purpose of the focus group was to establish professional perceptions of palliative care and inform part of the question development for the survey that would take place in Phase 2. It was therefore identified that a purposeful sample of experts in Cystic Fibrosis and palliative care would be approached to take part in the focus group.

5.4.1. The Venue

In preparation for the focus group it was important to establish a suitable venue for the meeting to be held. Within one of the research sites there is an established research department that allows researchers to have private rooms free of charge. As there was no additional funding for this research it was felt this would be an appropriate venue to hold the focus group.

A room was selected that had an oblong table. This would ensure that all the participants would be able to see each other with ease and there was a suitable position identified for the field note taker that would allow them to be able to see all the participants to assess non-verbal communication. The digital recorder to record the focus group had two microphones one of which would be placed at each end of the table. It was established that the room would accommodate 10-12 people.
5.4.2. The Participants

There were a few important issues to consider in whom to involve in the focus group. It has been suggested that participants in focus groups are often selected as a homogenous group because they have something in common which is of interest to the researcher. Taking into consideration the participants’ social and cultural backgrounds may also help them to talk more freely about the topic although this does not include the participants’ views or attitudes regarding a situation (Ivanoff & Hultberg 2006, Peek & Fothergill 2009). Several disciplines are involved in the care of patients with Cystic Fibrosis and it was important to ensure those doctors, nurses, clinical nurse specialists and allied health care professionals were invited to participate as these are the 4 main groups who deliver care to patients with Cystic Fibrosis on a daily basis.

Consideration was given to the number of focus groups needed in order to achieve the intended aim of the study as well as the actual numbers of participants needed for the focus group. On average the recommended number of participants should be somewhere between 4 and 12 (Kitzinger 2005; Peek & Fothergill 2009; Liamputtong 2011). Numbers of participants are based on ensuring there are enough participants to have a discussion but not too many that people may feel intimidated if talking in a large group (Smithson 2008). The rationale for undertaking one focus group related to the expertise and diversity of the expert participants and for pragmatic reasons related to cost and time constraints. The focus group was not segmented by age, class or sex which can indicate the need for more than one focus group.
(Liamputtong 2011). An important issue for the focus group is ensuring that the population of Cystic Fibrosis and palliative care are reflected within the participants. It also became clear that representation within the group was from a centre where Cystic Fibrosis and Palliative care teams were aiming to deliver a more integrated service and another centre where there was limited integration. This resulted in the opportunity to understand perceptions and experiences from different viewpoints.

Both teams were approached and those who met the inclusion criteria were made aware of the focus group at the multidisciplinary meetings. The names of appropriate team members were confirmed by telephone and email addresses were confirmed. A letter of invitation and a study information leaflet was forwarded to potential participants asking them if they would be interested in taking part in this focus group. A copy of the invitation letter and study information leaflet can be viewed in Appendices 5 and 6. Those approached were informed that this would take place on site at Trust A. They were given a deadline of response time of three weeks and a reminder was sent out at the end of the second week. There were eleven invitation letters forwarded and eleven responses received all who agreed to take part in the focus group. As there was no additional funding for the team from Trust B to come to Trust A, the researcher managed to secure funding from a research budget within her current place of work. This secured funding for all travel expenses. It was felt face to face would be better as opposed to using other means such as video linking/Skype due to the sensitive nature of the topic. Following the participants’ agreement to be part of the focus group a list of potential dates
and times were forwarded to them. It was possible to achieve agreement on
dates and times of eight out of the eleven participants. They were reminded
about the focus group start time and venue the day before.

5.4.3. Timing of the Focus Group

The focus groups should last between 1 to 2 hours. This ensures the
participants do not find the discussion tiring, they may run out of issues to
discuss or they may need to leave due to personal reasons (Liamputtong
2011). The researcher was also aware that there would need to be sufficient
time to allow the group to warm up before discussion occurred (Conradson
2005). In view of these issues the focus group timing was for an hour and a
half and was towards the end of the day to ensure staff would then be able to
leave for home in time if needed.

5.4.4. The Moderator

It is recognised that in market research focus groups often have people
specifically employed to facilitate/moderate the focus group, however with
health and social sciences it is identified that it is often the researcher
themselves who will moderate the focus group and an independent note taker
is encouraged (Smithson 2008; Holloway & Wheeler 2010). The researcher
considered the skills needed prior to undertaking the facilitation of the focus
group and made sure she was informed on the specific skills required. The
literature suggests a number of characteristics that inform a good moderator.
These are listed in Table 13 below
Table 13. Characteristics of a good moderator of Focus Groups

<table>
<thead>
<tr>
<th>Characteristic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensitive to the needs of the participants</td>
</tr>
<tr>
<td>Non-judgemental about the responses from the participants</td>
</tr>
<tr>
<td>Respect of the participants</td>
</tr>
<tr>
<td>Open-minded</td>
</tr>
<tr>
<td>Have adequate knowledge about the project</td>
</tr>
<tr>
<td>Good listening skills</td>
</tr>
<tr>
<td>Good leadership skills</td>
</tr>
<tr>
<td>Good observation skills</td>
</tr>
<tr>
<td>Patience and flexibility</td>
</tr>
<tr>
<td>Be able to withhold own opinions or assumptions</td>
</tr>
</tbody>
</table>

(Liamputtong 2011)

The researcher had many of the suggested characteristics and had also previously moderated a focus group. Whilst there is some suggestion that a moderator should be neutral to the research project (Smithson 2008) in contrast, it is also alluded to that an awareness of the moderator’s social position and awareness of how their behaviour can impact on the interaction of the group is as important as well as their own experience encouraging discussions (Wilkinson & Kitzinger 1996; Stokoe & Smithson 2002). In addition to this the researcher needed to consider the position of the moderator in maintaining control of the group. The aim as the moderator was to ensure that all participants were given the opportunity to speak and that the topic guide which was created from a review of the literature was used as a mechanism to guide the questions to the experts in the focus group (Munday 2006; Bryman 2008). The researcher did have experience as a leader in facilitating groups and supporting groups of people when discussing difficult issues.
Within the focus group the moderator ensured the experts were introduced to each other and that the scene in terms of introduction to the topic was set. All the participants had received an information leaflet prior to the focus group and were given the opportunity to ask questions again when consent was taken prior to the beginning the focus group. The focus group participants controlled the running of the group themselves to some extent. Following the introduction to the topic and the opening issue for discussion the experts naturally generated discussion themselves covering most of the topic guide. When there was a natural pause within the group the moderator clarified what had been said. If it was clear that there was no more to add to that particular issue then the moderator took this as an opportunity to move the conversation forward by introducing the next area of discussion from the topic guide.

5.4.5. Note taker

A note taker is essential in focus group interviews as the moderator is unable to coordinate the focus group and take notes at the same time. The note taker was selected to support the moderator to check to see if any issues have been overlooked. The note taker was introduced at the beginning of the focus group and her role was explained. She sat outside of the focus group so she was not in any of the participant’s eye view so as to distract any of the participants (Hennink 2007).

The note taker had responsibility for the starting and stopping of the digital recorder equipment throughout the interview as well as being responsible for any support participants required throughout the meeting. It was established
that no fire alarm tests were anticipated throughout the focus group. The note
taker selected was a clinician who would be familiar with some of the
language and conversations that may be used within the group in the hope
that additional information could be captured. The note taker was also known
to have clear easy to read hand writing. The moderator and the note taker met
on two occasions prior to the focus group. On the first occasion the note taker
was made familiar with the venue for the meeting and the equipment that was
to be used. The topic guide was shared with the note taker and the note taker
was advised on the type of information that would be helpful to capture. This
included observing interactions between the group members, activity within
the group and facial expressions that would be written as field notes and
memos (Willis et al. 2009). The moderator checked with the note taker at the
end of the focus group, to confirm that all areas of the topic guide had been
discussed.

5.4.6. Consent

The participants were informed in the participant information sheet that written
consent would be obtained prior to starting the focus group. All participants
were offered a consent form and all agreed to sign; a quiet area in the room
was secured for this to allow discussion and confirmation of understanding of
the focus group process to take place. The participants were given a copy of
their signed consent form and the original was placed in the researcher’s site
file. Consent was obtained in line with the research site stipulations of the
Committee for Clinical Research and South East Surrey Coast ethical
recommendations. A copy of the consent form can be viewed in Appendix 6.
5.4.7. Equipment

A digital recorder was used for the focus group. Additional batteries were taken to ensure taping was continuous. The note taker checked the equipment at the beginning and throughout the focus group to ensure recording was taking place. This equipment allowed for the information to be immediately downloaded onto a secure password protected computer for analysis.

5.4.8. Topic Guide

A topic guide for the focus group was designed based on information from the literature review. In order to answer the research questions and to identify questions to be asked in the questionnaire that would inform the survey in phase 2 of the study areas of current service provision between Cystic Fibrosis and palliative care would be established as well as reasons for referral, barriers to referral and how appropriate seeing patients earlier in their disease trajectory might be (See Appendix 7).

5.4.9. Analysis of the Focus Group

The data from the focus group was downloaded onto a password protected lap top. The information was transcribed verbatim by the researcher and organisation and analysis of the data was aided by NVivo 10. When using focus groups the general principles of conducting interviews apply (Birks & Mills 2011). A wide margin on the right was left so that the researcher could add comments whilst reading the focus group. The focus group was read several times and constant comparative analysis was applied. From this nodes were created and from this one theme was generated with categories
and sub categories and analysed applying the principles of a constructivist Grounded Theory approach. Further data analysis is illustrated in Chapter 6. A copy of the interactions of the participants within the focus group can be viewed in Appendix 8.

The focus group was undertaken in a safe environment with an experienced moderator. A topic guide was used to inform the discussions within the focus group. It was clarified at the end of the focus group that all areas of the topic guide had been explored. The findings from the focus group can be viewed in Chapter 6. This chapter will now discuss the survey applied in phase 2 of the research.

5.5. Phase 2: Survey

5.5.1. Development of the Questionnaire

There was no current tool available to apply to this survey therefore it was necessary to develop a questionnaire to ensure the data collection answered the research question. It was clear from the information gathered from the focus group that one of the areas to explore within the survey would be referral patterns between Cystic Fibrosis and palliative care. As the literature had highlighted a limited number of articles relating to how Cystic Fibrosis and palliative care teams currently work together, exploring existing models of service delivery would be important questions to include within the national survey to establish current practice. It was also important to be able to recognise the demographics of the services. Therefore the questionnaire was structured into three domains namely, referral patterns, models of care and demographics. In designing the questionnaire it was important to consider the
five distinct types of question that refer to behaviour, beliefs, knowledge, attitudes and attributes (Schonlau et al. 2002; Dillman et al. 2009). The design of the questionnaire and the wording of the questions were based on the recommendations by De Vaus (2002) and can be viewed in Appendices 9 and 10. The validity of the questionnaire was also considered. Validity determines what survey questions to use, and ensure researchers are using questions that measure the problems that matter. A survey is considered to have validity if it measures what it plans to measure (De Vaus 2002). Content validity was achieved through ensuring the concepts to be examined were defined from within the literature and construct validity was achieved through the expertise of the participants from the Focus Group informing the questionnaire development.

Survey Monkey a leading provider of web-based surveys was approached to help with the development and processing of the survey. A combination of open and closed question formats were used. A structured questionnaire was developed within some of the questions a free text area was available if respondents had anything extra they wanted to add in to the answer. Numerical rating scales were used for some of the questions. The questions were set up to ask non-threatening, simple questions first, to engage the participant, no personal details were asked at the beginning of the questionnaire as this has been determined as a precursor to the respondent losing interest (Bowling 2009). The questionnaire had twenty one questions to be answered. Questions 1-13 related to referral patterns between the Cystic Fibrosis and Palliative care teams. Questions 14-18 related to models of care.
and ways of working. Questions 19-21 related to demographics around length of time in the speciality and multi-disciplinary representatives within the team.

The web-based provider helped in making the questionnaire look as clear as possible by using colour and layout which would hopefully encourage respondents to complete the questionnaire. A copy of the final questionnaire can be viewed in Appendix 11.

5.5.2. Length of the Questionnaire
Within the literature it is suggested that the length of the questionnaire is not too long as this can increase reluctance on the part of respondents to complete it. A questionnaire that is too short can also bring in to question the value of completing it (De Vaus 2002; Bowling 2009). Twenty one questions were built into the questionnaire split into three sections.

5.5.3. Pilot of Questionnaire
The questionnaire was piloted by two independent clinical teams who were similar in speciality to the teams that the survey was aimed at which is recommended in the pilot phase (De Vaus 2002). The researcher met with both teams to gather feedback and discuss the questionnaire. Following the pilot three changes were identified which related to the wording of the questions. The questions were answered in the same way which indicated the tool being reliable and unambiguous. The changes were made to the questionnaire which was subsequently forwarded to South East Coast Surrey
ethics committee for approval. Following approval of the questionnaire the survey was forwarded to the identified population.

5.5.4. Sample

The sample population for the survey was purposive. The rationale for this relates to aiming to identify specific answers to questions between Cystic Fibrosis and Palliative care teams. This type of sampling is recognised as being useful when this method is being used (De Vaus 2002). The Cystic Fibrosis Trust holds a list of all the adult specialist Cystic Fibrosis centres within the United Kingdom. These centres were selected as the sample with their respective Palliative care services. There were twenty-three adult Cystic Fibrosis centres on the website in 2012 (Cystic Fibrosis Trust 2012). The Palliative care teams were identified and in total forty-six questionnaires were forwarded.

5.5.5. Set up of the Survey

Both Cystic Fibrosis and Palliative care teams were contacted initially by telephone to establish who the clinical leads were for both teams. This helped in establishing if Cystic Fibrosis teams had access to Palliative care teams in the hospital, ensured that the email address for the clinical lead was correct and informed the teams that a questionnaire would be forwarded to them in the coming weeks. It was identified that all the Cystic Fibrosis teams had access to Palliative care.
5.5.6. Methods Employed to Increase the Response Rate

Two weeks in advance of the survey, a letter was forwarded to inform potential participants of the survey and that the survey would be forwarded to them. A covering letter was forwarded to the study population with an information leaflet explaining the rationale of the study and the survey and can be viewed in Appendices 12 and 13. A reminder was noted in the letter regarding the pre email telephone call that had occurred in the hope this would help them remember that the survey was going to take place. Within the email an URL link was embedded that would take the participant directly to the questionnaire. Email reminders were forwarded to participants at two time points, the first at three weeks and the second at six weeks.

5.5.7. Data Analysis

Data from the survey was inputted into a Statistical Package for Social Sciences (SPSS). Descriptive statistics were collated and can be viewed in Chapter 6. There was a complication identified within question nineteen of the study that related to the numbers of professionals within each team and whole time equivalents (WTE). It became apparent that this question would only accept whole numbers. This particular issue was not highlighted in the pilot phase of the survey. The following section will describe the conduct of the interviews that informed phase 3 of the study.
5.6. Phase 3: Patient and Professional Interviews

In order to understand the perceptions of patients and professionals about a referral to Palliative care in patients with Cystic Fibrosis semi structured interviews were undertaken. The view of employing semi structured interviews when using a Grounded Theory approach is discussed within the literature (Bryant & Charmaz 2010; Birks & Mills 2011). It is recommended that having a too structured interview can inhibit flexibility to respond to the participant and in allowing the conversation to flow (Birks & Mills 2011). It is however alluded to in Grounded Theory that an interview guide can be helpful in aiding the conversation, but that researchers must expect it to alter as data gathering continues (Bahora et al. 2009; Bryant & Charmaz 2010; Birks & Mills 2011). An interview guide was developed for both patients and professionals to ensure that similar kinds of information were discussed with all the participants. The information in the interview guide was based on information documented in the literature review identifying that there was a need to undertake this research and data gathered in Phases 1 and 2 of the study that required a more in depth understanding. A copy of the interview guides can be viewed in Appendices 14 and 15.

5.6.1. Recruitment of Patients

Following discussion at both Trusts key clinical members of staff were identified who would help to identify patients to participate in the study based on the inclusion criteria. Both sites had information regarding the study and were equipped with patient information leaflets. Since Trust B was located several hundred miles away from the researcher’s base it was decided
following discussion with the clinical team that the researcher would identify a period of time where she would reside locally to recruit both patients and staff to the study. Due to location, it was easier for the researcher to be more spontaneous in terms of recruitment and subsequent interviewing of both patients and staff at Trust A. Participants who were identified by the clinical teams were recruited into the study by the researcher. Initial conversations took place either by email, telephone or face to face contact. Following confirmation of interest in the study by the patients a suitable time and place was secured for the interview to take place. It was identified that data saturation would occur when the researcher recognised that the categories that had been developed were robust as no new properties were established (Charmaz 2014). Memos were used to support this development.

5.6.2. Recruitment of Professionals

Both Cystic Fibrosis and Palliative care teams were made aware of the study and discussed at the multi-disciplinary team meeting. Both multidisciplinary team meetings are attended by all members of their team. Therefore dieticians, physiotherapists, occupational therapists, doctors and nurses were made aware through this meeting on both sites. Ward staff were made aware through meeting with the ward teams and information leaflets for professionals were offered for further information. In using the principles of a Grounded Theory approach it was important to make all staff and patients who met the inclusion criteria to be aware of the study. This is important since as the data emerge there is a possibility that different issues may be raised that may warrant interviewing different types of patients and /or professionals. As an
example it became clear that talking to patients who had already met a Palliative care team would be helpful after analysing one of the transcripts. The sampling was purposive to begin with and became theoretical as data emerged. This is supported in the literature (Sbaraini et al. 2011). As the researcher was not at the research sites daily, two clinicians were identified, one on each site, to help with the recruitment process. Names were forwarded to the researcher of interested professionals and they were subsequently followed up by email or telephone. Following this if they continued to be interested in the study a suitable date, time and venue was secured and communicated to the professional by email. Trust B interviews were all planned over a two week period. Trust A interviews occurred over a period of six weeks.

5.6.3. Place of the interview

In Trust A it was possible to secure a room for patients who were attending as out patients. Patients with Cystic Fibrosis who are in hospital all require single rooms due to the risk of cross infection from other patients, therefore privacy was secured for all patients.

Patients were given the opportunity to be interviewed either at the respective hospitals or at home. Of the eight patients interviewed six patients were in hospital which took place at a convenient time for the patient. The remaining two patients were well and out of hospital and decided to come to the respective hospital to be interviewed. The interviews with professionals were secured at a convenient time for them.
All interviews except one were face to face and in the hospital. One professional from Trust B had to cancel the interview due to personal circumstances. She was keen to be interviewed and therefore the interview was conducted on the telephone. The consent form for this professional was emailed, signed and returned by email.

5.6.4. Conduct of the Interviews

The day before the interviews all participants were contacted to ensure they were still able to participate. Prior to the interview starting the researcher ensured that the information leaflet had been read and understood and any outstanding questions were answered, illustrated in Appendices 16 and 17. A consent form was signed prior to the interview. A copy was given to all the participants and a copy placed in the research file at each site. These are illustrated in Appendices 18 and 19. Following the interview consent was obtained again to ensure the participants were happy with everything they had said and for extracts to be used to confirm the development of themes. The interviews were taped using a digital recorder that had been used in the focus group so the researcher was familiar with the equipment. Although within the literature it is identified that tape recording when using a Grounded Theory approach is not always recommended (Glaser 1998), it is supported when the researcher is a novice and whilst the researcher has undertaken other forms of research, experience remains limited therefore it was appropriate to digitally record the interviews (Birks & Mills 2011). The recordings were downloaded onto a password protected computer. Field notes were documented immediately after the interview to capture observations made of non-verbal
communication used by the participants. A copy of one of the field notes maintained can be viewed in Appendix 20.

Participants were made aware that they could stop the interview at any time. Water and tissues were made readily available for the participants. Throughout the patient interviews the researcher checked regularly to ensure the patients did not feel too breathless to continue as breathlessness can be problematic for patients with Cystic Fibrosis. On both research sites staff support had agreed to support either patients or staff if anyone became distressed following the interviews.

The interviews were transcribed verbatim and organised using NVivo 10 stored on a password protected secure laptop. NVivo is a qualitative data analysis computer software package recommended for use in storing and analysing qualitative data (Holloway & Wheeler 2010). This software was used as an additional tool to support data analysis as opposed to actually analysing the data itself. The researcher transcribed four of the interviews, two patients and two professionals. A recommended external transcribing service was recommended and approached to transcribe the remaining thirteen interviews; this was mainly to help with time constraints. Each interview was listened to at least twice before any analysis commenced. A dropbox system was used to transfer the interviews between the researcher and the transcriber. The
external transcriber deleted the transcripts immediately following the transfer of the completed transcription.

5.6.5. Analysis of the interviews
The information from the initial data gathering were coded before further information was collected as supported in the literature (Birks & Mills 2011; Charmaz 2014). The data were coded using constant comparative analysis. In constant comparative analysis data is compared with data to ascertain similarities and differences, interview statements and incidents are compared within the same interviews and then with other interviews. In the researcher’s study data were coded initially line by line, this is followed by intermediate coding and finally advanced coding and theoretical integration which are seen as reconnecting the data (Birks & Mills 2011). Undertaking constant comparative analysis occurred concurrently with the data collection.

5.6.6. Constant Comparative Analysis
The process of constant comparative analysis aids the development of the emergent theory (Holton 2007). The rationale for applying constant comparative analysis is to observe if the data supports the development of the emerging categories (Bryant & Charmaz 2007).

In this study open coding was established with line by line coding of the data. This helps in keeping the researcher close to the data (Charmaz 2014). An extract of this can be viewed in Appendix 21. The initial coding phase helped the researcher identify further areas for data collection that were lacking. For
example it became clear that being able to interview patients who had both been referred to Palliative care and those who had not been referred was important in identifying perceptions of Palliative care. Line by line coding with gerunds is recognised as a heuristic way of bringing the researcher into the data (Charmaz 2014). This helped in recognising meaning and helped direct the researcher in areas for further exploration. The constant comparative method is recognised as consisting of three distinct phases. The process involved firstly comparing incidents with incidents that lead to the development of codes. Further incidents were subsequently compared with existing codes. Codes were compared with codes from which groups of codes were collapsed into categories. Ongoing developments of codes were compared with categories and categories were compared with developing categories. It was recognised that this process of constantly comparing results in generating data that results in abstract categories rich with meaning (Bryant & Charmaz 2007).

Following the development of open coding the researcher engaged in focused coding which in recognised as the second phase in Grounded Theory (Charmaz 2014). The development of the focused coding was a result of identifying codes that appeared on a more frequently occurring basis in the initial coding phase. In defining focused codes Charmaz (2014) suggested a list to incorporate into the development of these. Table 14 illustrates this list.
Table 14. Guide for Developing Focused Codes

<table>
<thead>
<tr>
<th>Guide for developing Focused Codes  (Charmaz 2014)</th>
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</thead>
<tbody>
<tr>
<td>What do you find when you compare your initial codes with the data?</td>
</tr>
<tr>
<td>In which ways might your initial codes reveal patterns?</td>
</tr>
<tr>
<td>Which of these codes best account for the data?</td>
</tr>
<tr>
<td>Have you raised these codes to focused codes?</td>
</tr>
<tr>
<td>What do your comparisons between codes indicate?</td>
</tr>
<tr>
<td>Do your focused codes reveal gaps in the data?</td>
</tr>
</tbody>
</table>

The development of focused codes was not a linear process. The development of the focused codes resulted in the researcher going back to the initial data to re-explore findings. The analysis process is discussed further in Chapter 6.

5.6.7. Anonymity and Confidentiality

Participants involved in the interviews were coded, and names and details of hospital trusts were removed. Only the researcher was able to link the identity of the participant with the tape and transcript. All information was stored on a password protected computer. Research files were stored in a locked fire proof cupboard on all sites. Consent was requested again after the interview to ensure that participants were in agreement with anything that had been said being used to inform the research findings and that quotes from interviews would be used to support findings. Participants were aware that research supervisors would have access to the transcripts but that names would be removed. It was important to ensure that the two sites were not identifiable throughout the study. Professions were removed to reduce the risk of participants being identified.
5.6.8. Ethical Considerations

All research needs sensitivity, caution and respect for the physical and emotional well-being of participants (Kendall et al. 2007). In general, interviews with patients who may be near the end of life and their carers need not cause significant distress and are often valued by participants (Casarett et al. 2003). No reason exists as to why the management of patients who may die should be excluded from the scientific scrutiny necessary to improve care for patients/carers with non-terminal conditions. However it is recognised that gate keeping can be seen as the hesitance of well-meaning health care professionals in suggesting patients/carers for research studies (Kendall et al. 2007; Rees & Hardy 2003; White et al. 2008). Patients were made aware that they could stop or withdraw from the study at any point without prejudicing care. Ethical considerations for this study are listed in Table 15 below. In addition to this a risk assessment of this study was undertaken and can be reviewed in Appendix 22.
Table 15. Ethical Considerations for all 3 Phases of the Study

<table>
<thead>
<tr>
<th>Voluntary Participation of Research Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients and professionals would be invited to take part in the study. Attention was given to informed consent, ensuring no harm came to the patient or professional and confidentiality, anonymity and privacy were maintained.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Managing distress of patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Additional support was arranged through the hospital Palliative care team, Cystic Fibrosis teams or GPs.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>To manage any distress of staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>Additional support from staff support teams would be made available or the psychological support team.</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>To manage any complaint/concern discussed with the team</th>
</tr>
</thead>
<tbody>
<tr>
<td>The patient was advised to discuss issues with either a member of the team or the appropriate patient advice and liaison service.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Managing distress of the researcher undertaking the interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>Additional support from colleagues and supervisors.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>To ensure safety of the researcher</th>
</tr>
</thead>
<tbody>
<tr>
<td>The researcher worked within the guidance of the lone worker policy.</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>To maximise patient autonomy and anonymity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use of encrypted data.</td>
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</table>

<table>
<thead>
<tr>
<th>To maintain privacy and dignity throughout the interviews</th>
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<tbody>
<tr>
<td>The study achieved ethical approval and the survey was taken back to ethics following the pilot phase.</td>
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</table>

<table>
<thead>
<tr>
<th>To ensure the researcher has undertaken Good Clinical Practice Training</th>
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<tbody>
<tr>
<td>Attended before and updated during the study.</td>
</tr>
</tbody>
</table>
5.6.9. Reflexivity

It is recognised in the literature the importance of the researcher taking a reflexive approach towards their study (Andrew & Halcomb 2009; Holloway & Wheeler 2010). The researcher had previously recognised that she had over twenty-five years’ experience in palliative care and therefore, with that, came pre-existing ideas about palliative care as a speciality and how patients should have access to it. The use of memos and a reflective diary aided the researcher in identifying actions and feelings. This did not occur at a single time-point. The memos were revisited to support learning from previous interactions. Field notes were made following interactions with participants where the researcher documented about emotions or thoughts that occurred following each data collection. Discussion with the researcher's supervisors also facilitated personal reflections of pre-existing thoughts and assumptions regarding Cystic Fibrosis and palliative care. Although the researcher was in a position with overall responsibility for a palliative care service she recognised that she had no direct managerial responsibility for any of the staff members who might be interested in taking part in the study. Being in clinical practice resulted in the researcher re-visiting the data on more occasions than necessary and keeping memos and a diary to ensure misinterpretation of the data did not occur.

5.6.10. Theoretical Sensitivity

It is suggested that theoretical sensitivity can be a concept that is difficult to fully understand (Birks & Mills 2011). As a researcher it was important to analyse what the researcher knew about the topic in advance of the research.
As alluded to in Chapter 3 the researcher had expert knowledge in palliative care but much less so regarding Cystic Fibrosis. The key issue for the researcher was not to apply theoretical schemes to the research data based on previous experience of palliative care. The researcher used her previous experiences as a conceptual comparison with the data and used previous experiences to stimulate thinking using a reflective diary to capture these thoughts.

5.7. Summary

This chapter has provided detailed information relating to the methods applied in this study. It is clear that a mixed methods approach was the most appropriate to ensure the research questions were answered. Quantitative and qualitative research alone would be insufficient to understand the research topic due to the complexities of the research questions to be answered. Information has connected the rationale between the selections of the research design, the research methods used and illustrated issues for analysing the data and discussed validity of the study.
CHAPTER 6: FINDINGS OF STUDY

6.1. Introduction

Mixed methods underpin this research and three methods of data collection were used to ensure the research questions were answered and the aim of the study achieved. In Phase 1 of the study a Focus Group was conducted to understand professional perceptions of palliative care and to inform the development and content of the Phase 2 survey. Phase 2 data were gathered through a survey whereby a questionnaire was forwarded to recognised adult Cystic Fibrosis specialist centres within the United Kingdom and their respective palliative care Teams. Phase 3 data were gathered through semi structured interviews with both patients diagnosed with Cystic Fibrosis and professionals caring for patients with this illness. The patients and professionals involved in the study were recruited from both Cystic Fibrosis and palliative care specialties within the two research sites. The data generated were analysed in the context of a mixed methods methodology. The principles of a constructivist Grounded Theory approach were used to explore the qualitative data. Constant comparative analysis was used to analyse the qualitative data. Themes, categories and sub categories are presented within this chapter. Data from the survey was analysed and presented through descriptive statistics and interpretation of all three phases is discussed.

Initially the theme identified in the Focus Group will be explored. Extracts from the participants in the Focus Group are presented throughout this section to support the development of the theme. The extracts are illustrated in italics
and supported by the name “FG” and CF (Cystic Fibrosis) or (Palliative care) PC to denote the speciality the extract is from. This is followed by a number which allowed the researcher to maintain anonymity of the participants. The findings of the Focus Group clearly demonstrated how part of research questions one and two were met and generated areas for particular questions to be poised to inform the development of the questionnaire in Phase 2. This section will now present the findings from the Focus Group in Phase 1 and will conclude with a summary of this phase. The research aim and questions are illustrated below as a reminder to the reader.

<table>
<thead>
<tr>
<th>Research Aim</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. To explore the experiences and perceptions of patients with Cystic Fibrosis and health care professionals regarding palliative care and the acceptability of this as a service early in the patient’s disease trajectory.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Research Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What are patients with Cystic Fibrosis and health care professionals’ experiences and perceptions of palliative care?</td>
</tr>
<tr>
<td>2. What are the barriers and facilitators of a palliative care referral in Cystic Fibrosis?</td>
</tr>
<tr>
<td>3. Are the services for the provision of palliative care within Cystic Fibrosis integrated as part of an multi-disciplinary team</td>
</tr>
</tbody>
</table>

### 6.2. Phase 1. Findings from the Focus Group

The data gathered from the Focus Group answered part of research questions one and two which explored professional perceptions and experiences of Palliative care and informed the questions to be asked nationally to Cystic Fibrosis and Palliative care Teams in Phase 2 of the study. Whilst undertaking a focus group with patients was not possible due to issues regarding cross infection other methods could have been initiated such as
interviews. The rationale for not selecting to interview patients at this stage related to the literature review in Chapter 3 which recognised perceived barriers from professionals in referring patients to palliative care some of which were related to how professionals felt patients perceived a referral to palliative care. The researcher wanted to first establish the perceptions of professionals and to explore the reasons why they may not perceive palliative care as acceptable, the information from which would be used to inform the interviews with patients. The data from the Focus Group were organised using NVivo 10 that was downloaded onto a password protected lap top. One over-arching theme was generated from the Focus Group using constant comparative analysis, named ‘Digging a Hole’. This theme was conceptualised through comparing interview statements from participants within the Focus Group. The participants used this term to explain the concern they had in discussing palliative care. The participants also illustrated the concept of ‘Digging a Hole’ when they discussed how concerned they were about starting conversations about palliative care that resulted in discussions about death and dying. Recording what was observed throughout the Focus Group was important in capturing non-verbal communication which substantiated the verbal information gathered.

The following data are presented with coded extracts from the focus group interview to support the generated themes. Table 16 below offers descriptive details of the participants that took part in the focus group. The participants included nurses, doctors and allied health care professionals.
The participants were a purposive sample of eight multidisciplinary professional experts working in either Cystic Fibrosis or palliative care. All the participants were female. As the research topic related to exploring early Palliative care in patients with Cystic Fibrosis, purposeful sampling was used as the researcher required information on Cystic Fibrosis and palliative care from specialists who had relevant experience working with this group of patients (Holloway & Wheeler 2010). The participants within the focus group were expert representatives from the two research sites. Table 17 illustrates the theme that has been generated from the Focus Group. The following section will discuss the theme, ‘Digging a Hole’ which related to talking about palliative care. The meaning of palliative care was generated as a category with the term palliative care and barriers and facilitators as sub categories. These data were instrumental in answering part of research questions one, and two and in developing questions for the survey in Phase 2.

6.3. Theme 1: Digging a Hole

The theme generated through constant comparative analysis related to the professionals’ description of digging a hole. The meaning of palliative care and

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**Table 16. Description of the Focus Group participants**

<table>
<thead>
<tr>
<th>Speciality</th>
<th>Experience in speciality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cystic Fibrosis</td>
<td>5 years</td>
</tr>
<tr>
<td>Palliative care</td>
<td>Over 10 years</td>
</tr>
<tr>
<td>Palliative care</td>
<td>Over 10 years</td>
</tr>
<tr>
<td>Cystic Fibrosis</td>
<td>Over 10 years</td>
</tr>
<tr>
<td>Cystic Fibrosis</td>
<td>5 years</td>
</tr>
<tr>
<td>Cystic Fibrosis</td>
<td>Over 10 years</td>
</tr>
<tr>
<td>Cystic Fibrosis</td>
<td>Over 10 years</td>
</tr>
<tr>
<td>Cystic Fibrosis</td>
<td>Over 10 years</td>
</tr>
</tbody>
</table>
what this inferred to professionals and the connotation of the term Palliative care were created as a category and sub category. Facilitators and barriers towards palliative care were recognised as a sub category within this theme.

Table 17. Theme generated from Focus Group

<table>
<thead>
<tr>
<th>Theme 1</th>
<th>Category</th>
<th>Sub-Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Digging a Hole”; talking about palliative care.</td>
<td>Meaning of palliative care from the professionals viewpoint</td>
<td>The term palliative care Barriers and facilitators of referral to palliative care</td>
</tr>
</tbody>
</table>

What the referral to palliative care purposed and when the referral to palliative care should occur was discussed repeatedly throughout the Focus Group. The majority of the group were in agreement that referral to palliative care should occur at any time depending on the needs of the patient. The experts repetitively alluded to the barriers and facilitators perceived regarding referral to palliative care

6.3.1. Meaning of Palliative Care to Professionals

The participants were cognisant that there was an association with death when palliative care was mentioned. They referred intermittently throughout the Focus Group about the term Palliative care and acknowledged that they denote palliative care as the symptom control team. Seven of the participants discussed that they perceived palliative inferred more than dying and tried to inform other professionals about what Palliative care services could offer to patients.
6.3.1.1. The Term Palliative care

The professionals acknowledged how they rarely talked about Palliative care and used different language to describe the Palliative care team to patients and other members of the multi-disciplinary team. The term symptom control was used interchangeably with palliative care to describe the service. Three of the professionals captured this in their extracts below. From the first extract there was laughter within the group with reference to rarely talking about palliative care. The extract was from one of the Cystic Fibrosis professionals who seemed embarrassed by what she had said but looked relieved when she saw others in the group agreed with her. It was interesting as although she said she did not have a problem with the name, what was said and the tone of her voice almost said the opposite inferring a problem with the term palliative care. This detail of tone of voice and body language were acknowledged through the field notes that were kept throughout the Focus Group.

*We rarely talk about palliative care (laughter), when you’re first introduced to it or if we talk to some of our doctors about how helpful they can be. I always say to help with your symptoms if I see them in clinic…it’s about sometimes misconceptions the dying thing. So we re-name you basically. I don’t have a problem with the name but others do (FG/CF Professional 8).*

*But it does… we do introduce ourselves as the palliative care team so even if you’ve introduced us as the symptom control team (laughter from the group) and I will often couch that as both with the symptom control and Palliative care team and we do a whole range of things so that’s usually my starting point because then if I’m actually then there to talk about symptoms they actually know that they can talk about advance care planning if they want to…Because the reality is they probably are going to die so you know you find yourself going Palliative care are going to see you but you’re not going to die emmm yet you start like and your just digging yourself this massive hole (pretends to dig a hole) (FG/PC Professional 2).*
We don’t access Palliative care and I’m guessing that’s because we associate it with death and almost don’t want to refer, maybe we should (FG/CF Professional 1).

As new understandings of the needs of people at the end of life emerge, communication needs to be unambiguous with groups of people with different perspectives and needs (Palliative care Australia 2008). The language that professionals use and the meanings that are attached to specific terms become increasingly problematic. The lack of consistency in the use of terminology has created confusion as professionals try to communicate and understand the needs of different cohorts of people facing the challenges of providing palliative care. From the Focus Group both Cystic Fibrosis and palliative care professionals referring to the term symptom control was a way of easing the introduction of palliative care but also felt it helped describe what the palliative care team did. One of the professionals in Cystic Fibrosis summed this up in the extract below.

I think it’s a lot easier on the ward (to use the term symptom control) and it’s a lot easier to talk about especially with the patient and the family it’s not palliative care, we’ve got 1 week 2 weeks left it. It’s more welcoming it’s like the cancer word of old the ‘C’ (cancer) the dreaded word. And at the MDT when palliative care is mentioned you know the patient might still have years to live. Patients need the help and symptom control helps them understand what palliative care does (FG/CF Professional 5).

From the literature it is clear that there has been a rapid growth of palliative care services. This has raised several problems in the way that services are perceived by both the public and professionals and therefore accessed (Ahmed et al. 2004). Specific problems have resulted in a reluctance to refer
to palliative care because of misunderstandings of what it offers, or fear of its association with imminent dying (Ahmed et al. 2004). One of the Palliative care professionals below described how she constantly feels like she has to sell the palliative care service. It was also interesting interpreting the response of laughter when the palliative care professional stated that “I can do optimism” There was a sense of togetherness within the group recognising that whilst palliative care is associated with death and dying, not all palliative care specialists think that way. The sense of togetherness was illustrated through non-verbal communication and a physical movement of the group members towards the table they were sitting around signifying that there were shared concerns about the introduction of palliative care.

*I can do optimism … (huge amount of laughter within the group) but you know I think the team the palliative care team has a responsibility to work with the other teams and to negotiate there’s a lot of negotiation and selling yourself, selling palliative care to the other teams so that it seems helpful to patients and the families (FG/PC Professional 5).*

The participants recognised that not everyone understands the term palliative care and discussed how when introducing palliative care they always need to explain what it is actually about. They discussed their perception of how patients respond when Palliative care is mentioned.

*Well exactly and I was going to say that at the start like what does palliative mean and could you just get rid of it, people haven’t a clue I would never for the first time explaining somebody that somebody from the palliative care was going to see them without feeling like I had to explain what that was so you can’t ever I don’t think I could ever cos they just say palliative care are coming to see you without carrying on and explain because you know straight away the look you’re going to get that knowing look of. Oh God she’s telling me I’m dying (FG/CF Professional 6).*
The last extract discussed changing the name of palliative care to something more easily understood. In studies relating to perceptions of Palliative care in non-malignant disease this association of the term palliative care with death and dying has also been identified (Dharmasena & Forbes 2001; Waterhouse 2013). There is over a decade between these two studies and yet from the current research, palliative care continues to be perceived as an end of life care service.

6.3.1.2. Barriers and Facilitators to a Palliative care Referral

A discussion evolved regarding access to palliative care services for symptom control earlier in the patient’s disease trajectory and not just focusing on end of life care. The issue of palliative care being used in a wider context was considered in one of the areas where a more integrated approach between the Cystic Fibrosis and palliative care teams was developing. The concept of the reason for referral to palliative care was important for some of the team to discuss and to confirm the rationale behind making a referral to palliative care. For some it was clear that a referral to palliative care would only be initiated when the Cystic Fibrosis team perceived they were struggling to control patients’ symptoms and consideration of referring to the palliative care team would normally only occur leading up to the patient’s death, if at all. The participants acknowledged that selected barriers to palliative care were professionally led rather than related to patient perceptions. These related to previous experience and misconceptions about when to refer to palliative care.
The extracts below recognised the difficulty in palliative care involvement at the end of life, and also recognised how the professionals themselves may act as a barrier. They considered the difference in the mind-set between Cystic Fibrosis and palliative care indicating that Cystic Fibrosis focused on curative care and Palliative care on death and dying. This is reflected by professionals from both specialities in the extracts below and was reiterated by three others.

*I guess one of the barriers to palliative care not being involved is if you only involve them at end of life…. cos you don’t know when end of life is so actually more often than not you’re going to miss it or you will be involved too late to get to know anyone. I think we hesitate cos we don’t know when to refer and we are all about making the patient better whereas…maybe pall care might want to stop some treatment (FG/CF Professional 3).*

*And I think that mirrors other areas where at times sometimes we have the impression that actually the barrier is the professionals being able to acknowledge where things are at rather than the patients and families sometimes there is a sense of relief for patients and families when you realise that’s to be talked about (palliative care) um but that’s I accept very hard when in a professional role you are in a curative mode we’re in a slightly different position in terms of how we work so that’s easier, although palliative care doesn’t mean no to active treatment (FG/PC Professional 2).*

Professionals’ lack of clinical experience was regarded as a barrier with an inability to see changes in patients' status that indicated a serious decline in health. Having triggers to support clinicians was discussed as a way to overcome this barrier and become facilitative to referrals. Furthermore traditional training has focussed primarily on curative measures, health professionals were considered to find the complex transition from curative to palliative treatment difficult to acknowledge (Gardiner et al.2011). This was described by one of the professionals in Cystic Fibrosis below.

*But perhaps if you were a CF team that didn’t access palliative care triggers would be useful in terms of educating the team and cos it’s really the only way*
that relationship is formed is through positive experiences and steps and when the CF team feel the benefit of having that relationship that’s how the relationship evolves further so if you have to start somewhere so I suppose if you are a team where you are having to access a palliative care team that’s not necessarily integrated then having those triggers, like a trigger at transplant to start that relationship off are probably really helpful to give ideas of when you can introduce it (FG/CF Professional 8).

The perception of palliative care not having the resources to support patients with Cystic Fibrosis was highlighted as a potential barrier by one of the professionals working within Cystic Fibrosis and reflected on experience within Europe.

I think it’s changing cos I have this discussion frequently in different European meetings and I think actually CF teams are wanting it more and more and are looking around to see where they can find pall care teams to work with them so as said earlier resources probably is a really key thing cos for many palliative care teams really haven’t got any resources to add CF to their emm working lives and the time it takes the learning takes but there’s a big rounds well now of CF teams trying to look not just here but everywhere, but resources must be a huge barrier (FG/CF Professional 5).

The participants who were developing services between Cystic Fibrosis and Palliative care recognised how the palliative care team being visible and approachable on the in-patient unit really helped in facilitating referrals. This is captured in the extract below.

Having palliative care on the ward round and coming to the MDT has really helped in terms of us making other referrals, when we see the team we think oh I must just refer xxx (FG/CF Professional 5).

The participants also discussed how patients can act as facilitators and communicate through social media about seeing the palliative care team
Equally that can work in that it’s helped them and they some of them do then say something positive about it cos they’re always on face book or texting each other they know about each other’s treatments faster than we do sometimes (FG/CF Professional 7).

The extracts from the focus group reflected what others in the literature have alluded to. Several papers concluded barriers towards referring patients to Palliative care are that many physicians had significant gaps in their knowledge about hospice referral policies and practices and that knowing when to refer to palliative care is complex (Bradley et al. 2002, Ahmed et al. 2004).

6.4. Summary

The Focus Group has offered significant insight into the perceptions and experience of professionals regarding palliative care. Based on the findings from the Focus Group, areas for further questioning in the survey include the meaning and understanding of palliative care, referral patterns to palliative care, time points for referral between Cystic Fibrosis and palliative care that will further question barriers and facilitators of referrals to palliative care (Appendix 11, Questions 2-13). The literature review highlighted gaps in determining current models of service provision between Cystic Fibrosis and palliative care teams which would be important to explore further within the questionnaire (Appendix 11, Questions 14-19). These three areas informed the domains for the questions to be asked in the national survey.

6.5. Phase 2. Findings from the Survey

The following section will present the findings from the survey that informed phase 3 of the study. The survey was conducted to examine in more detail the
issues that had been raised by the Focus Group in Phase 1. The participants of the Focus Group were approached as they were considered to be experts either in Cystic Fibrosis or specialist palliative care. Given that these participants were drawn from 2 sites, they were not therefore representative of the national picture.

It is clear from the Focus Group data that issues raised related to the perceptions and meaning of palliative care and when to refer to palliative care services, as well as acknowledging the different ways that teams work. The questionnaire was therefore categorised into three domains. Section 1 related to referral patterns, section 2 models of care and section 3 demographics of respondents. The findings from the survey will be presented under these three domains using categorical data and descriptive findings.

It was important to be mindful that in questioning professionals about perceptions of palliative care and how services are offered, is often dependent on the organisation, its ethos and the way in which it values and integrates with palliative care. Organisational culture and service provision are influenced by many factors within the current health service. Organisations, on this occasion hospitals, are thought of as systems ordered to gain certain goals and outcomes. Whilst these organisations can be seen as iterative processes of communication and interactions, they are prone to become systems of habit however they are not without the potential for transformation (Fonseca 2002).
Thus individuals may respond according to their own personal views or simply as a product of their organisational culture. This is important in considering the analysis of the survey and its wider applicability.

The questionnaire was forwarded to all adult specialist Cystic Fibrosis hospital based centres that were registered at the Cystic Fibrosis Trust in 2012 (23 registered centres). Their potential respective palliative care teams were identified based on location. This second professional group were also approached to ascertain their view on current service provision for patients with Cystic Fibrosis, irrespective of whether or not the Cystic Fibrosis and palliative care teams currently had a working relationship. It was clarified, by telephone, that all Cystic Fibrosis teams had access to a hospital palliative care service. The lead team member for the respective team was identified by telephone and the questionnaire was forwarded to them via email. The following section will demonstrate the response to questions.

6.5.1. Responses to Answered Questions

The overall response rate to the survey was 61% (28/46). Of the respondents, the palliative care team return was higher than the Cystic Fibrosis team, 57% (n=16/23) were specialists in palliative care versus 41% (n= 11/23) were specialists in Cystic Fibrosis. Of the 28 respondents who did return the questionnaires, eighteen questionnaires were completed fully. Of the ten remaining partially answered questionnaires, 8 respondents completed questions 1-13 regarding referral patterns but did not complete the subsequent questions on models of care, perhaps reflecting their clinical
experience thus far. Of the 10 respondents who did not complete all the questions 7 were from palliative care, 2 were specialists in Cystic Fibrosis and one was unknown as only the first question was completed. Additional comments were documented in thirteen of the questions with the most documented in questions 2, 18 and 21. These questions related to why specialists felt patients with Cystic Fibrosis may not be routinely referred for palliative care, any changes that they would make to the existing service and a general comments box for additional information.

One respondent completed only questions 1-4. This was a specialist unit working in palliative care and stated that Cystic Fibrosis teams did not refer to palliative care therefore they were unable to complete any of the ongoing questions. One respondent completed the first question only, stating that Patients with Cystic Fibrosis were not referred to palliative care and hence did not complete any of the remaining questions. Below Table 18 illustrates the response to the questionnaire.

The following section will describe the data from the first domain of the questionnaire which relates to referral patterns between Cystic Fibrosis and palliative care teams
<table>
<thead>
<tr>
<th>Questions answered</th>
<th>Numbers of Respondents</th>
<th>Response by Speciality</th>
</tr>
</thead>
<tbody>
<tr>
<td>All questions</td>
<td>18/28</td>
<td>CF (9)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>PC (9)</td>
</tr>
<tr>
<td>Questions 1-13</td>
<td>8/28</td>
<td>CF (1)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>PC (6)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>UK (1)</td>
</tr>
<tr>
<td>Questions 1-4</td>
<td>1/28</td>
<td>PC</td>
</tr>
<tr>
<td>Question 1</td>
<td>1/28</td>
<td>CF</td>
</tr>
</tbody>
</table>

### 6.5.2 Referral Patterns

When professionals were asked if patients with Cystic Fibrosis were routinely referred to the palliative care team, 100% (n=28) of respondents replied with less than 50% of the teams indicating they routinely refer patients between Cystic Fibrosis and palliative care. In aiming to understand why patients with Cystic Fibrosis may not be referred and to further understand the perception of a referral to palliative care the participants were asked why they thought such referrals may not occur. Fourteen of the fifteen teams who do not refer gave a reason (24 reasons in total). The most common reasons were that professionals are unsure when to refer Patients with Cystic Fibrosis to palliative care (n=9), this was followed by over half of the respondents stating that Cystic Fibrosis teams themselves can manage palliative care needs.
The issue of patients not wanting to be referred to palliative care was stated by 4 respondents. This issue was discussed further in the interviews in Phase 3. Table 19 below illustrates the reasons why patients are not routinely referred to palliative care services. Interestingly the palliative care team response is higher than the Cystic Fibrosis teams in regards to difficulty in knowing when to refer to palliative care services.

Table 19. Reasons why patients are not routinely referred to Palliative care services (n=24 responses from n=14 respondents)

<table>
<thead>
<tr>
<th>Reason</th>
<th>Number of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>SPC</td>
</tr>
<tr>
<td>CF teams can manage PC needs</td>
<td>3</td>
</tr>
<tr>
<td>Implications for staff training</td>
<td>2</td>
</tr>
<tr>
<td>Lack of PC resource</td>
<td>1</td>
</tr>
<tr>
<td>CF patients not wanting referral</td>
<td>2</td>
</tr>
<tr>
<td>Difficulty re timing of when to refer</td>
<td>6</td>
</tr>
</tbody>
</table>

In terms of referral numbers, the majority of teams (n=14) stated that between 1 and 9 Patients with Cystic Fibrosis are referred to palliative care in a 12 month period. It was also evident that four teams referred 10-25 patients and three teams referred 25-49 patients. One team recognised that on occasion a patient can be referred several times during the course of one admission.

Interestingly of the teams who answered positively to Patients with Cystic Fibrosis being routinely referred to palliative care, 54% of these referrals were made through the Multi Disciplinary Team meeting. Alternatively referrals are commonly made by telephone. In addition one team stated they would make referrals directly to the consultant via email.
This needs to be interpreted in the context that 11 of the teams stated the numbers of Patients with Cystic Fibrosis seen annually by their service. For those who saw >100 patients per year, one referred 25-49 patients to palliative care per year, 3 referred 10-25, 4 referred 1-9 and one referred no patients to palliative care. The two smaller centres who reported seeing 50-100 patients per year both referred 1-9 patients.

For the 9 Cystic Fibrosis teams that reported seeing >100 patients per year, they referred between 3-8 patients for transplant each year. Three of these teams considered transplant a trigger for referral to palliative care, interestingly these three teams all reported weekly meetings between Cystic Fibrosis and palliative care and a ‘fully integrated’ service. Within this question the respondents were given the option of considering if their service was fully integrated, partially integrated or not integrated at all. A fully integrated service was one where Cystic Fibrosis and palliative care teams were working closely together meeting regularly, using shared guidelines for the management of symptoms. For the 6 teams who did not use transplant as a trigger, three of them stated that they thought this might be important. Of the 6 teams, 3 never met with their palliative care team and 3 met with them ‘as needed’ and they described their services as partially integrated (n=1) or not integrated (n=5). The two smaller services (50-99 CF patients per year) referred 3-5 patients for transplant and one considered transplant a trigger for referral to palliative care, neither had regular meetings with the palliative care services.
Full integration referred to Cystic Fibrosis and palliative care teams working closely together meeting regularly, using shared guidelines for the management of symptoms. This was described by four teams (3 above plus one smaller team). Only two of the teams recognised that they were working towards developing shared guidelines, therefore none of the services were currently providing a fully integrated service based on the offered definition. Over half the teams do not have joint meetings (56%); but for those who do meet (44%) they tend to meet on a weekly basis. The teams acknowledged the level to which they work together. The majority of teams, 54%, identified that they did not feel they were integrated at all. Partial integration was reported by 31% respondents and 15% felt they were fully integrated and worked closely together.

In trying to understand what teams’ cognise about the meaning of palliative care they were offered to select from two definitions, the definition that best fitted their current practice. The majority of the respondents declared that the most recent WHO (2002) definition best reflected their practice (early referral as opposed to end of life). The definition selected by 81% of the respondents declares that palliative care should be offered to patients early in the stage of their illness in conjunction with other therapies that are intended to prolong life. Interestingly one team acknowledged that they use the first definition (end-of-life) but believed the 2nd (early referral). A further team identified that in their service most teams are referred for the former definition and are not referred earlier in the disease pathway.
Participants were invited to consider 9 reasons for referral between Cystic Fibrosis and palliative care and they could select more than one reason for referral by their service. 26/28 responded and selected each of the 9 responses on 4-23 occasions (total 122). The most common response (selected 23 times) was that patients would be referred for symptom control. The prevalence of symptom burden is recognised in patients with Cystic Fibrosis especially within the last week of life (Dellon et al. 2010). The question in the survey did not differentiate at what stage of the patient’s illness would trigger a referral for this. The second most frequent reason was patients being referred for end of Life Care (19), with advance care planning, support with end of life care pathways and psychological support being the joint 3rd most common reasons for referral (16 each). Community Support and Support with family discussions may be lower as patients with Cystic Fibrosis tend to be admitted to hospital for end of life care due to strong relationships with the team who will have had many family discussions over the course of the illness and patients wishing to be in a safe environment (Bourke et al. 2009). The reasons for referral are illustrated in Figure 6.

The newer definition of palliative care (WHO 2002), which teams stated working to, identifies an important element in addition to symptom control, psychosocial support and focus on quality of life. It also includes access to early palliative care which runs alongside and in conjunction with other treatment modalities. Interestingly the response to ‘When to introduce palliative care’ did not reflect that teams were working to this expanded definition with few respondents selecting introduction early in the pathway or
for support in the community setting. A referral early in the patient’s disease pathway was perceived to be one of the least important times to introduce palliative care. This may be important as it has been suggested that introducing palliative care too late in the disease pathway can cause distress to both patients and families (Robinson 2009). Timing of referral to palliative care can be viewed in Figure 7. This issue was further explored with patients in Phase 3 of the study.
6.5.3 Models of Care

In aiming to establish the current model of care provided, participants were invited to select a description of their current service provision between Cystic Fibrosis and palliative care. This was to try and understand if the teams were working together at any stage of the patient's illness or if it was focused more towards end of life care.

In the questionnaire teams were asked to describe the current model of care that exists between Cystic Fibrosis and palliative care as either a) consultative only for patients with complex needs, b) concurrent management throughout the course of Cystic Fibrosis, c) concurrent management but only once
treatment options limited. The models of care were based on information from the National Council for Palliative Care and are the most common practices of hospital Palliative care teams (NCPC 2006). In this question 18 responses were received; half of these described concurrent management versus consultative (as required) only. Where there was concurrent management 2/3 occurred only when treatment options had become limited rather than throughout the course of the illness. Currently there are no nationally agreed guidelines on the referral criteria between Palliative care other specialities (APM 2012). Referral criteria to Palliative care and models of care are individually constructed by teams based on the service they offer.

Resource issues were not highlighted by teams in a previous question as being a limiting factor of service provision. Thus it is more likely that the observations could be related to difficulties in determining the referral criteria for this group of patients. Interestingly one team suggested that Cystic Fibrosis teams may still not refer patients with complex needs as they feel they have the skills to manage them and therefore education as to what Palliative care can offer is likely to be invaluable to both patients and staff. This is addressed further in the results of the patient/staff interviews.

Regarding guidelines for referral between services, 17 respondents answered this question with a universal response of 100% of teams identifying that there were no specific guidelines for referrals between Cystic Fibrosis and Palliative
care. Interestingly two teams identified that they were working towards specific guidelines between Cystic Fibrosis and Palliative care teams. Other teams identified that they worked within generic guidelines for referral to Palliative care. As there is a lack of clarity relating to referral between the teams specific guidelines may help in determining when to refer patients with Cystic Fibrosis to Palliative care.

Respondents identified that they were split in terms of whether they would make any changes to working together. Fifty per cent of teams reported that they would make some changes to the way they worked together whilst the remaining 50% believed the service worked well as it was. This is despite only four services reporting a fully integrated working service although only two of these were working towards shared guidelines. Of the teams that said they would like to make changes to the existing service, this was more likely to be raised by palliative care teams. However a third of Cystic Fibrosis teams commented that they wanted to increase links with palliative care teams. The perception is that palliative care feels that although the relationship is good with Cystic Fibrosis teams the service could be delivered in another way and would like to change some elements of the current service provision.

6.5.4 Demographics of Respondents

It is difficult to interpret all the results relating to the Whole Time Equivalent within each service due to the set-up of the question being unable to accept
non whole numbers. Whilst teams tried to complete this, some of the numbers are difficult to interpret. It would seem that from the respondents all teams have access to some members of the multidisciplinary team. The majority of the professionals had experience of either working in Cystic Fibrosis or palliative care for over ten years representing professionals who would have knowledge about the service delivery for both specialities.

Additional comments generated from free text in the questionnaires can be viewed in Table 20 below. Cystic Fibrosis teams commented that they felt they could manage patients palliative care needs. They also recognised that they would like a more formal structure to the teams meeting up.

**Table 20. Information Generated from Additional Comments from the Questionnaire**

<table>
<thead>
<tr>
<th>Additional Issue</th>
<th>Cystic Fibrosis</th>
<th>Palliative care</th>
<th>Cystic Fibrosis and Palliative care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of clarity and guidance about when to refer to Palliative care including a lack of referral guidelines and trigger points.</td>
<td></td>
<td></td>
<td>Nine respondents recognised clearer referral guidelines and or triggers for referral between the 2 teams would be helpful Cystic Fibrosis n=3 Palliative care n=6</td>
</tr>
<tr>
<td>Team working and relationships</td>
<td>5 respondents felt that CF teams could manage patients without additional support from Palliative care 3 respondents from CF said they would like there to be a more formal structured approach to meeting with Palliative care</td>
<td></td>
<td>Seven respondents acknowledged that they wanted to work closer together with respective Cystic Fibrosis and Palliative care teams Cystic Fibrosis n=4 Palliative care n=3</td>
</tr>
</tbody>
</table>
6.6. Summary

The findings from the survey demonstrate that there is no universal process within Trusts in terms of referral to palliative care services. It is clear that a lack of clarity around the timing of referral of patients with Cystic Fibrosis to palliative care is one of the key areas for further development. Transplant has been raised as a time point to consider referral to palliative care which does not fit with current practice according to the feedback from the questionnaire.

The majority of teams meet on an “as required” basis and there are no shared guidelines to support the working practices between the two teams currently. The key issues that have emerged from the survey are:

- lack of clarity around when to refer to Palliative care,
- patients are considered to be referred too late,
- lack of shared guidelines to work towards and there is limited integration between teams.

The concept of timing of referral to palliative care along with perceptions of palliative care will help form the topic guide for the semi structured interviews in Phase 3 of the study.

6.7. Phase 3. Findings from Patient and Professional Interviews

The following section relates to the findings from the semi structured interviews conducted within Phase 3 of the study. Three themes have been generated from the interviews, namely, understanding of palliative care, establishing connections with service providers and constantly redefining the future. The three themes can be viewed in Table 21 but will be discussed
individually throughout this section. The patients and professionals generated the same themes with an exception in theme 3 where the sub category of patients receiving affirmation from external sources regarding their life expectancy was identified. The interviews were organised using NVivo 10 and were categorised into nodes. The themes have been created using the principles of Grounded Theory analysis from the evolving categories and sub categories. The themes will be explored separately and dialogue from the interviews will show the emerging categories through the process of constant comparative analysis. For reference the extracts are coded Patient or Professional followed by a number to ensure anonymity of the participant.

Table 21. Themes generated from Interviews

<table>
<thead>
<tr>
<th>Theme 1</th>
<th>Theme 2</th>
<th>Theme 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding of palliative care</td>
<td>Establishing connections with service providers</td>
<td>Constantly redefining future</td>
</tr>
</tbody>
</table>

6.7.1. The Interview Participants

There were seventeen participants who agreed to be interviewed. Of these seventeen interviews, nine were health care professionals caring for patients with Cystic Fibrosis. The remaining eight interviews were patients with Cystic Fibrosis. One of the patients (Patient 02) had been diagnosed with the disease in the last decade and was older in age than the other participants. In terms of the interviews that took place on the research sites, eight of the interviews took place at a Trust B and nine took place at a Trust A. Information relating to the participants involved can be viewed in Tables 22 and 23 below.
The following section will present findings from Theme 1 which relates to the patients and staff understanding of palliative care.

### 6.8. Theme 1: Understanding of Palliative care

Understanding the term palliative care and what a referral to palliative care means is recognised as a known limiting factor in the referral process of patients to palliative care services. Heterogeneity in what palliative care services offer in different areas and in different organisations is complex and
equity in the way services are configured is dependent on localities (Ahmed et al. 2004). Understanding palliative care has been generated as a theme with categories of perceptions and knowledge of palliative care and concurrent active Cystic Fibrosis treatment and palliative care. Sub categories of the term palliative care, access to information, time-points of referral to palliative care and access to services have been identified. Table 24 demonstrates the theme, categories and sub categories. A copy of the development of theme 1 can be viewed in Appendix 23.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Category</th>
<th>Sub-Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding of palliative care</td>
<td>Perceptions and Knowledge about Palliative care from both patients and staff</td>
<td>The term palliative care</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Access to information</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Time points of referral to palliative care</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Access to services</td>
</tr>
<tr>
<td>Concurrent Active Cystic Fibrosis treatment and palliative care</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

6.8.1. Perceptions and Knowledge

The perceptions and knowledge of palliative care was generated from the data as a category. Perceptions and knowledge are influenced by a myriad of issues and in this study influenced the ways in which patients and staff understood palliative care. Studies have previously demonstrated that patients with other non-malignant conditions have recognised palliative care as being synonymous with end of life care (Metzger et al. 2013).
6.8.1.1. The Use of the Term “Palliative care”

Patients and staff had different views about the term palliative care. There was confusion varying from not understanding palliative care at all to only associating it with death and dying. Some of the professionals had experienced positive responses when they first discussed a referral to palliative care with patients with Cystic Fibrosis. One of the professionals in Cystic Fibrosis discussed that sometimes it is the professionals who are more concerned about referring to palliative care than patients are of actually hearing about the service. This is reflected in an extract below from one of the professionals. Interestingly this was also identified within the Focus Group data.

A lot of the patients really appreciate meeting palliative care early and don’t find it as scary as we think they will. I think sometimes staff perception is oh God but actually they (patients) go oh brilliant you know so and so who I spoke to on facebook met you and you were really helpful with them and I have this horrid pain and they can’t get rid of it can I talk to you about it and they find it really positive. I think sometimes staff preconceptions of palliative care rather than patients because they won’t have any because they won’t know what it is if they haven’t met pall care probably. Patients don’t always find it as scary as we think they will I think sometimes staff perception oh God don’t refer them to palliative care because they’ll think they’re dying… I’ve only ever I think once mentioned to patient about palliative care and they’ve said no thank you I don’t need them I’m not dying but every other time the patients have always been receptive (Professional/CF 01).

In one of the research sites the professionals acknowledged a change in the way palliative care was referred to and described what that change meant. They recognised that palliative care was no longer considered solely at the end of life and should be associated with helping patients to live with a life threatening illness both earlier in their disease and for longer periods of time. This resonated with the definition of palliative care (WHO 2002) but not all
professionals thought this. One of the palliative care professionals described this below.

_Maintaining a quality of life within the, context of that life threatening illness. So whether that be through symptom control, emm maintaining their independence making sure that they can ye know they’re socially able to function emmm support for their family and sometimes it’s actually the small things that make all the difference. And that’s very much about what palliative care is, I’ve learned very much that it’s not about end of life care it’s not purely about dying anymore. It’s about living with a life threatening illness but living well with a life threatening illness and seeing patients early and longer possibly._ (Professional/PC 02).

Another of the palliative care professionals acknowledged that they considered the term palliative care to refer to patients who were in the last year of life. Interestingly if patients were referred earlier in their disease they referred to their service as either symptom control team or described being there to provide other support services. This was also discussed by other professionals. The rationale behind this was to ensure the patient was not distressed at being introduced to palliative care. This is of interest as one would believe that palliative care specialists would feel confident in introducing their speciality but not in the case below.

_I would describe palliative care as care for a person that has been diagnosed with an incurable disease or illness; however you want to describe it. And particularly I feel palliative care is or should be involved in the last year of the patient’s life. Obviously, we are asked quite early on in the stage of the illness, and then I would describe myself as a specialist who is here to look maybe at symptom control or to provide psychological support. We don’t want to upset anyone with what we say_ (Professional/PC 04).

One of the Cystic Fibrosis professionals discussed how they understood that all Patients with Cystic Fibrosis have palliative care needs. She became quite
angry when talking about palliative care being introduced and indicated that patients would not believe that palliative care is not about dying. Her anger seemed to depict her own view of palliative care and was transferring this onto what she thought the patient would say.

**R. Do you think palliative care may have an impact on hope and the future?**

No. Not at all! But I think it’s more the stigma that, for our patients anyway, it’s about stigma. And they all have... in my opinion they all have their little milestones, if you like, as to stigma attached to it, so it’s like, for example, once you start using a certain nebuliser – that’s because... the other one isn’t working and they’re not working any more. Do you know what I mean? So the... there’s like a little and I had a really in-depth conversation with the patient just before Christmas who – and in fact I’ve known her since I first qualified, she obviously feels comfortable with me and she’s saying, ‘This last year I’ve been in hospital three times. So if were to bring in a palliative care nurse, even at that point, she might not believe me. She’s not going to believe me (Professional/CF 06).

**R. Because of what palliative care means?**

Yes.

**R. Which is?**

That it’s the beginning of the end. Yes, yes. I mean our patients are all palliative all the time regardless. But it’s at what point is that palliation the beginning of the end? And that’s the difference with our patients. I mean things, things are changing but they are different do you understand, you know, there are a lot of fitter patients through. But we’re also getting a cohort of patients that their... transition they are poorly and they’re in and out all the time. So they are having constant palliation because – and they’re the ones that the nurses think, ‘Oh for God’s sake, don’t do it if they don’t feel like exercising today,’ you know what I mean? (Professional/CF 06)

The association of palliative care with cancer is recognised as being an issue in understanding what the service can offer patients with non-malignant disease (Fallon & Foley 2012). One of the Cystic Fibrosis professionals described how difficult they find discussing palliative care issues. This
illustrated the need to help support Cystic Fibrosis clinicians in terms of education and training around principles of palliative care issues and difficult conversations.

What I usually say to patients is, because patients, when they’re palliative, they don’t understand it. Or they do and they immediately associate it with cancer. So I possibly kind of mention it in an offhand sort of way, palliative care is a term that is associated with cancer, it doesn’t mean death and dying and all that kind of thing, it’s just a term that’s used for sort of long term care or – I don’t know, I find it really difficult to broach it, very difficult to broach that sort of aspect of it, unless I’ve got a really good rapport with them. And I know the patient and I know that I can be open and honest and come straight out with it (Professional/CF 07).

For the patients there were mixed views about the use of the term palliative care. Patients felt that if it was explained properly there most likely was not a need to change the name to something else although this was not unanimous. For Patient 03 at the beginning of the interview she did not think it would be necessary to change the name but on talking about it she then changed her mind.

If you were coming to say, ‘Oh we’re going to help with symptom control,’ you’d think, ‘Oh yes; I’m feeling I’d like to have a relationship with her because she’s going to help me.’ Now, but right at the beginning I thought, ‘Ooh... changing the name won’t matter’ As we’re talking, yes probably because symptom control makes it easier to understand what palliative care is... maybe I do think it’s about death (Patient 03).

One of the patients raised an interesting point in that patients with Cystic Fibrosis are a younger population and they would search the term on the internet which will inform them that it has something to do with end of life care. In the extract below Patient 05 suggested that a better description of what palliative care is about would help. The information that is available invariably
relates to end of life care which may not always be applicable to this group of patients. This is described in the extract below.

Oh yes, I’d probably change it if – yes, if I mean, if people google it man. But, yes, unless of course you say, ‘I’m from palliative care, which means...better control of symptoms and blah, blah, blah.’ So yes maybe don’t change it just offer a better description (Patient 05).

Patients 06 and 08 also recognised that when they had symptoms they were not concerned with the name of the team they just wanted their symptoms eased. Patient 08 also acknowledged that over time the public view towards issues change but recognised that explaining that palliative care is more than death and dying was important.

I think it’s just a new generation growing up will learn it means a different thing. So it will be fading out in the end. You know, as they do with driving tests now, it’s all done differently, whereas my generation it was done differently. So they phase it out rather than change it. I think it would be a waste of time trying to change it. It will cause confusion. I think it’s better phasing it out and the next generation will come through and will know it means something different but people need to explain it better. When you’re sick you just want help doesn’t matter about the name (Patient 08).

The term palliative care continues to have an association of death and dying. It has been recognised that from a professional perspective the name supportive care is better than palliative care (Fadul 2009). The perception is that supportive care does not take away hope from patients and families and in the cancer population has encouraged oncologists to refer to the palliative care team (Fadul 2009). There appears to be a gap for both patients and staff in understanding what the term palliative care means. The patients would in
the main, be in agreement with the term being the same if there was better explanation around what the service can offer.

6.8.1.2. Access to Information

Both patients and professionals recognised that information relating to palliative care as a service and what it has to offer could be portrayed in a better way. Palliative care staff discussed how not being part of the Cystic Fibrosis information that was available to patients did not make them feel part of the extended team and patients spoke of not knowing what palliative care could offer. It was acknowledged by both patients and staff that this influenced perception of palliative care and how it was viewed as being integrated with Cystic Fibrosis. For one of the professionals, working in palliative care and not being referred to anywhere in the Cystic Fibrosis patient information exemplified the lack of integration perceived between Cystic Fibrosis and palliative care which is captured in the extract below.

*I mean they think we do work together and we do I guess, it's just we are not on the patient information board with the rest of the MDT or mentioned in any of the booklets. (Looks disappointed) it's a bit gutting really you try so hard to be part of it all. What's that all about...? It's like we are the service that comes out of hiding when they (CF) want us (Professional/PC 02).*

Providing appropriate and timely information to patients has been recognised within the literature. Intrinsically linked to patient’s agreeing to have support from palliative care is their understanding of what the service is trying to offer. It has been identified that patients have often not had access to information about services delivering care (Ronaldson & Devery 2001; APM 2012).
Professionals in Cystic Fibrosis also described that they would like access to more information on what palliative care services can provide. For professionals 07 and 09 knowing what the palliative care service could offer was important. This is highlighted by Professional 07 in the extract below.

Interestingly although part of the core Multi-Disciplinary Team, she did not feel she had a role to play in initiating discussion about referrals to palliative care.

_I think for a start it would be nice for everyone to know exactly what palliative care do in our setting, if we know exactly what they do and what they can offer, because I don’t know exactly because obviously I don’t get involved in referrals maybe I should but am there supporting patients.. And I don’t know any other way or who else would help us know what palliative care can offer._ (Professional/CF 07).

From a patient’s perspective it was acknowledged that it was only when she was given written information about palliative care that she realised more than physical symptom control was on offer as part of the service to patients.

_Yes, I mean they were very clear with, with the role of kind of – well in terms of dealing with the sickness, they didn’t say too much about their roles generally. But they said about, you know symptom control and so that was very much what I was aware that they were there to sort of deal with. And yes they were helpful kind of with suggestions and talking things through. But it was only when I got given the leaflet a while later that I saw about the emotional and practical sort of side, because that’s never been sort of mentioned before_ (Patient 06).
A further patient acknowledged that not knowing about the service made her scared and if staff did not inform her about the service how would patients find out about it.

I, I didn’t really know what palliative care had to offer. If you knew what it was about it wouldn’t be scary. If the staff won’t talk about it then how can we ever know what it is? Yes and living with it and...you know, if you can get your pain under control and stuff like that, then you can get on with... a normal day and stay and go to work or whatever. So all that side of life... life planned out for you. And I think yes the ones that... might not die from it and those that might are as important (Patient 07).

The confusion of roles has been previously highlighted in the literature relating to other non-cancer diseases as well as difficulties around the organisation of health care and the unpredictable nature of the illness (Hanratty et al. 2002).

Knowing what the service can offer was important to the patients and highlighted in the extracts below. In the extract below Patient 04 felt left in the dark about services and what else was on offer.

Yes, or I think just be more open about what actually the service can offer, sort of maybe even just posters on the wall, you know, around the walls or something, just, because I wasn’t aware of much at all. And sort of I miss quite a lot. And yes it was like saying, they sort of mentioned to me about the sickness, nothing at all about any other things that could be talked through. So perhaps just more information available to patients about what they can access from palliative care really (Patient 04).

For one of the patients below being able to make a self-referral to palliative care was a consideration following access to an information booklet on what the palliative care team could offer.
Yes, I mean just if I, if I was sort of feeling very down, I don’t really know who I would tell in the CF team, So I suppose if a leaflet could be given out at the annual review, I think that would be helpful. But then I think, as well if there was some information, even if it was just a few posters around the ward. So kind of two approaches really, you know, so one at the annual review, but also if people come in and feel they need that bit of extra support or help with symptoms, you know, they can kind of access it in both (Patient 05).

From these extracts it is evident that clear information in a variety of formats for both patients and staff may help in determining what a palliative care service has to offer and help in empowering the patients to feel in control of the support they need. However, equity and barriers of access to palliative care for patients cannot go unnoticed. Local services define referral patterns and modify services accordingly. This has previously been recognised in the literature looking at access to palliative care services (Ahmed et al. 2004). The following section will discuss the second category of concurrent active Cystic Fibrosis treatment and Palliative care with sub categories of time points of referral to palliative care and access to services.

6.8.1.3. Concurrent Active Cystic Fibrosis Treatment and Palliative care

The benefits of palliative care being involved in cancer patients earlier in their disease process have been recognised previously (NICE 2004; Temel et al. 2010). This study looked at patients with lung cancer but acknowledged that in this group most health care professionals believed that palliative care is synonymous with end of life care. Some of the participants in the interviews found it difficult to consider active care for patients with Cystic Fibrosis and palliative care running in parallel.
It is recognised that patients’ survival with Cystic Fibrosis is increasing which is leading to an adult population living with this disease (CF Trust 2013). Patients with Cystic Fibrosis experience exacerbations of their illness and the unpredictability of what the future holds can be challenging for staff being able to determine if the patient will survive the next exacerbation or not Cystic Fibrosis. Professionals acknowledged that treating patients’ right to the end of life was important.

6.8.1.4. Time Points to Referral to Palliative care

The professionals discussed the confusion relating to when to refer to palliative care and both patients and staff highlighted transplant and the Annual Review as key time points to consider accessing palliative care. Six professionals indicated that lack of guidance regarding when to refer to palliative care was a barrier, which was directed towards the unpredictability of the patient’s prognosis. This was recognised by specialists from both areas signifying their belief that palliative care related to end of life. Two of the professionals alluded to this in the extracts below

*We haven’t got a clue when to see patients with Cystic Fibrosis because the CF team are so involved with their care we’re not sure when to push to see people likewise I think they’re kind of not sure when to get us involved because it’s hard to know when the patient is dying* (Professional/PC 09).

*Our patients are fighters being referred to palliative care would just be a sign that they’re dying and would not be helpful. They’re not like other patients, like cancer patients they live when they’re well and don’t want reminded that they’re dying and we know that’s what palliative care is about* (Professional/CF 07).
It was recognised by both staff and patients that waiting until transplant was discussed was too late and a referral to palliative care should happen earlier as the burden of symptoms could be problematic. One of the professionals in the extract below recognised that waiting until transplant was being considered might be too late to be seen by palliative care.

*I think we should use this as a trigger but..., I mean transplant is used for a kind of marker, but I think nowadays we have so many other patients that they, even though they’re getting close to transplant, you know, assessment or getting close to that point, they feel they still have quite a high burden of symptoms that’s the time to say, ‘Okay you should now be seen, you know, or just introduced to the palliative care team (Professional/CF 03).*

One of the patients was surprised to hear that one of her friends with Cystic Fibrosis has been referred for a transplant but has not been introduced to a palliative care team. She went on to discuss that she felt confused as to why she had been referred and her friend who was on the transplant list which she saw as a last resort had not been referred.

*Yes definitely. I was really surprised that she didn’t really have...it it’s like that is crunch time kind of thing. Actually I say that she’s now on the new drug Kalydeco. I think she loves it at the moment. But yes I would have thought that that would kind of go... perfect being referred when on the transplant list and seeing palliative care (Patient 07).*

A patient also recognised the importance of adequate symptom control when waiting to hear about a transplant to allow as normal a life as possible to continue. This patient was quite unwell and felt that his pain control had improved significantly following review by palliative care
Yes, when you’re on the transplant list, if you’re waiting, you’re forever waiting for that phone call. But if you can wait without pain, you know, that’s a relief so seeing the palliative care team before might be a better way. The palliative care team really helped me and my mum; don’t care what it’s called (Patient 08).

In one of the centres when transplant is considered the patient would be referred for review by palliative care. All the patients acknowledged that this would be a good time to trigger a referral. This is highlighted in the extract from one of the patients below.

*I think when you are being considered for transplant you kind of know things are not looking good, you’re kind of dreading that happening but I would imagine by the time you’re at that stage your symptoms are pretty rubbish and if palliative care can help with symptoms then we should be referred (Patient 01).*

Most patients with Cystic Fibrosis are invited to attend an “annual review” where they meet all members of the Multi-disciplinary team and have a review of their disease. At this review they have access to all the support services involved in their ongoing care. The patients and staff brought this time period up as a potential time to be introduced to palliative care or to at least be offered information on what the service provides.

*And obviously you see your consultant, physiotherapist, the dieticians and the diabetics. And again that can be quite informal. It’s like just having a chat and saying, you know, what they’ve got for you this time, and if you want to, you just chat and then all you have to do is come anyway so palliative care that could be introduced at the same time. Yes, then it would be, yes. I think we would accept it as part of the team (Patient 03).*

One of the patients recognised that knowing about palliative care when you are well and getting information at the Annual Review would be helpful.
I mean if it was introduced maybe a bit earlier, so like at an annual review or something, so it's just the standard thing, where someone actually saying, 'Look you need to,' or someone's coming to see you or might do from palliative care, at least that way, you know, people can have a chat then with someone about it, and if they're feeling well, that's fine, and if they're not, then at least they can get it fixed. So, but I think the whole kind of introducing someone like just like now coming in and saying, 'I'm from palliative care, I need to speak to you,' then, you know, okay. So yes, I mean, even if it's written information (Patient 05).

One of the professionals was cognisant of the fact that involving palliative care at the Annual Review through some form of communication would help with integration and make it seem like part of the Cystic Fibrosis service.

I don't know why we don't have palliative care at the annual review maybe we could have a DVD or written information that we could show the patients I don't know why we haven't thought about that before as all the other MDT are there. Maybe resource would be an issue (Professional/CF 05)

One of the palliative care professionals considered why palliative care might not be involved as routinely as they might be with other specialities and recognised that because the Cystic Fibrosis team is multi-disciplinary that the way Palliative care can help is limited.

They're not saying no to palliative care I think it's because there are other members of the team that deal with the I think the barriers are they're (CF) such a specialist team that I like as I said we get the left overs if you like so you've got the clinical psychologist dealing with all the psychology you've got the physio dealing with all the chest and the breathing you've got the consultants dealing with all the drugs emm you've got the dieticians dealing with all the nutrition emm so actually the barrier is so where actually do we fit in to this specialist team where is our role I think that's the only thing that they get stuck on is the symptom control it's kind of like we will get you in this way (Professional/PC 02).

It is evident that considering an introduction to the palliative care team is important around the time of the annual review to make it link in with the other
services that are available. Resource would not allow for all patients to be reviewed face to face but this could be a trigger to ensure information relating to palliative care is available.

6.8.1.5. Access to Services for Patients

Being able to access certain services in a timely way for patients was recognised as being important. The following patient extract recognised that access to some services was limited and was something she found quite frustrating as she was unable to do anything about this herself.

If I come in now and if I said to them today, ‘I think I could do with speaking to the counsellor,’ I don’t have, I know that a counsellor may be available, but I don’t feel that if I really needed to speak to a counsellor this afternoon, that somebody would be available, because I know it’s arranging the time and booking it. So I wouldn’t have confidence if I said, ‘Can I speak to a counsellor?’ It could be a week or two weeks before I got to speak to one, I don’t really know what’s on offer (Patient 01).

Patients felt strongly that if one centre was going to have access to palliative care then other patients in other centres should have similar access to ensure equity. They also mentioned how they felt disempowered on occasions as they were not always aware of the services that were available or how to access them.

I just think generally with the CF care, I think it’s really important to have an equitable experience. So if it’s something that’s going to be introduced here (research site) or whatever, I think it should, if it is found to work, it should be available to everybody that has a need for it. Also remember to make sure that everyone on the team remembers to talk about it – that’s the problem I had that with the psychologist, like no one was talking about the fact that it was there. And so yes just make sure that everyone kind of is aware that the resource is there, so then they can start referring them or let us refer ourselves maybe? (Patient 04).
Some of the professionals also acknowledged the challenge there might be from a resource point of view meeting the needs of the Cystic Fibrosis teams were referrals made on a regular basis. The following professional recognised that their service would more than likely be limited to hospital care although acknowledged that being accessible for outpatients might be a good idea.

We couldn't have that, I mean at the moment I'm not sure what their need will be because we don't even go in there so I don't have that many patients that they that are symptomatic or needing end of life care. I think to accommodate the clinic; we wouldn't have the resource for that at the moment. I'm not sure to be honest (Professional/PC 04).

This professional recognised that it would not be possible to stay for the whole of the multi-disciplinary team as this goes on for the whole day but has found a way of working with the team to be able to discuss patients and be informed of any new referrals. One of the professionals recounted this below.

I think because the MDT goes on all day I don’t think it’s possible from a resource point of view… so we tend to go in when the psychology team are there as that’s usually a good way of us picking up our patients but also I will say so these are the patients on my list that are in patients is there anybody else that you are concerned about elm and obviously they will be talking about patients that are due to come in or are coming in to clinic and also if I have had cos I am actually now referring a lot more of the CF patients out to the community palliative care teams am so that’s the number of referrals to CPC teams are now picking up emm and then I have been reporting back if I have had contact from CPCT I will be feeding that back to the CF team (Professional PC 02).

A further professional was concerned that waiting for symptoms to build up and then refer was too late and that resources may inhibit palliative care being able to see patients at an earlier stage in their illness.
You shouldn’t wait until the patient actually has got a lot of symptoms and a low lung function, that you’re then referring them for transplant – I think you should start thinking, ‘Okay that patient has a low lung function,’ but they might not have a lot of symptoms, but they’re probably going to have lots of symptoms very soon. So I think maybe, again it’s a matter of resources, we’ve got a lot of patients, we can’t get them to see everyone, you know, it’s quite a demanding job (Professional/CF 03).

Access to palliative care services is increasing however, it is important to remember that the majority of patients with Cystic Fibrosis will be seen by palliative care in the hospital setting. Seeing patients for a consultation, offering advice to the Cystic Fibrosis team and then withdrawing may help with the resource issue. Palliative care teams need to consider different models of care to ensure they do not review patients and maintain them on caseloads for indefinite periods of time. Offering advice and seeing patients intermittently can help in meeting the demands for access to palliative care (Quill & Abernethy 2013).

6.9. Theme 2: Establishing Connections between teams and Service Users

The second theme relates to the development of relationships between staff and patients and specialist teams. The relationship between the patients and the Cystic Fibrosis team is built up over a number of years. Staff and patients recognise the importance of this relationship and the familiarity of the environment in hospital. The table below illustrates the theme of relationships and the category and subcategories developed from the data using constant comparative analysis.
Table 25. Theme 2: Category and Sub Categories

<table>
<thead>
<tr>
<th>Theme</th>
<th>Category</th>
<th>Sub Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Establishing connections between teams and service users</td>
<td>Integrated Care</td>
<td>Development of relationships between staff and patients/specialist to specialist</td>
</tr>
<tr>
<td></td>
<td></td>
<td>The “fit” of Palliative care within the speciality of Cystic Fibrosis (both patients and staff)</td>
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6.9.1. Establishing Connections between Teams and Service Users

In a general health setting there is consensus that it is important to get to know a patient and their family and to understand their understanding and views about a situation and to build relationships (Radwin 1996; Luker et al. 2000; Canning et al. 2007; Skills for Care 2014). All the patients interviewed discussed the importance of having a relationship with the team that were caring for them. The patients discussed the significance of knowing teams by sight and how that helped in them feeling part of a community.

6.9.1.1. Integrated Care

The category of integration between the teams includes the sub categories of development of relationships and the “fit” of Palliative care within the Cystic Fibrosis team. The difference in team working was apparent between both sites. One site had a more proactive system between Cystic Fibrosis and Palliative care and the other team was much more limited in their relationship with Palliative care. The aim of this study was not to compare the two
research sites however the data gathered indicated that both research sites worked in different ways.

6.9.1.2. Development of Relationships

The importance of relationships was recognised by both patients and staff. One of the patients below described the importance of knowing people that are looking after them and seeing new people was disconcerting.

_The longer you know somebody, the more you have a personal contact with them. The more personal you can be as in, ‘How are you?’ I think you get your message across easier, you know, people are more confident to talk to you, like all the team here. I know xxxx is a dietician, I know the physios and I know everybody and it’s on a personal level and I think it’s better. One of the nurses is leaving...I am absolutely gutted. It’s like family you feel part of a community. For me knowing the palliative care team or anybody for that matter would be better for me and my family (Patient 08)._  

A professional from the Cystic Fibrosis team discussed how the relationship between the patient and professional is built over many years and reiterated the difficulty for patients in meeting new team members.

_We tend to build up hopefully quite a good rapport because they build up such a trust with the MDT within CF because you’ve looked after them for ten twenty years when you meet a new team member of the team it’s always going to be difficult at any time so if it’s done in an earlier more sort of relaxed way I think it works better so I think and every admission they will have met all those people emm and I think they get similar to psychology which we’re trying to change as well but so I suppose if you’ve been in for 15 years and you’ve never met someone from palliative care and then you do. I think I’d want the palliative care team to be able to build up a rapport with patients before they’ve started before they ended up in a tricky situation (Professional/CF 01)_
In one of the centres where palliative care is accessed on a more regular basis one of the Cystic Fibrosis professionals recognised how important it can be for the patients to be seen by someone they know and acknowledged the importance of seeing patients earlier.

*I think now, because there’s involvement early on, patients are used to getting the symptom control. And when they do, you know, when the moment does come and they are fighting infection and they’re struggling and everything, it’s not an alien person that comes to see them* (Professional/CF 03).

One of the professionals below acknowledged how staff became friends with the patients and viewed the relationship important in following the patient through from the beginning to the end of their disease. The blurring of boundaries between patients with Cystic Fibrosis and staff has been identified previously when it was disclosed that the circle of support other than including parents, siblings and families would also include various health care professionals that may be subject to obscured boundaries (Jessup & Parkinson 2009).

*So they know them totally in and out. Whereas I think for CF, in the CF world, I think it is different, because they have months and many years as a family and, you know, when I used to work in CF years ago, you know, we used to go out with them, become friends with them and we socialised with them, you know. I think, you know, any speciality that deals with the younger population, I think people just relate to it in a different way, and become much more protective and mothering that patient part of that doesn’t facilitate referrals to palliative care* (Professional/PC 09).

One of the patient extracts below discussed the importance of the Cystic Fibrosis staff and getting to know them as people and being seen as a person not just a patient. The sense of not being treated as a number but as a person
was important for all of the patients. The patient below became quite tearful when
considering how well the Cystic Fibrosis team knew him illustrating the strength of trust and the relationship that has been developed over time. The patient refers to “our girls” in reference to the clinical nurse specialists inferring the continued perception of the community spirit within Cystic Fibrosis

*I think it’s because they get to know you as people. And will listen to what you’ve got to say, where I come across people in different positions and we do find some professionals will treat you as another number, you know, you’re just a patient and I have had crossed wires. And I think, because our girls know us, and they know, you know, what’s important to us and they know us as individuals, we trust them. So you feel comfortable with that* (Patient 03).

The need to meet professionals earlier and to be able to build some kind of relationship was reiterated as being important for the patients. One of the patients recognised how difficult it was being admitted into an environment where you were not known, whereas being admitted with the Cystic Fibrosis team in the specialist centre he didn’t need to explain anything about medications.

*It does help a lot because I think with patients with CF you kind of, you get people that are kind of, you know, live their life by it, if that makes sense. So, you know, and the doctors would know, ‘Okay we know he’s been a little bit rough, you know, but he’s not that bad,’ type of thing. Whereas a new team or someone that doesn’t know me, would be like, ‘Bloody hell, he feels this and he feels that.’* So yes I think building up a relationship with patients is very good. There was a couple of times last year though that I kind of needed to get in to hospital, but obviously rooms were very busy, so I had to spend some time between home and the local hospital. But I had pretty much a punch-up with them to get a room for myself. So yes, yes, so, but I mean fair play to here like, as soon as a room became free, it was like two days they got me up here. So, but that was pretty horrible actually because the local hospital doesn’t know anything about you, and you get quite a bad rap, you know (Patient 05).
The professionals acknowledged how getting to know teams better had helped in developing a more integrated service. Although this was not the same for everyone the professional below recognised how it was only when she spent some time with the palliative care team that she realised what they could offer. The Cystic Fibrosis professional appeared surprised by the response of the palliative care team which appeared to be based on a perception that palliative care had to see every patient and would not be able to support staff alone.

*I had a chat with one of the palliative care team about something that a patient had said to me and I wasn’t quite sure what I should have said back. It was really cool actually because I was a little bit worried that they would just say they would go and see the patient and I wasn’t sure how the team would feel about that, but actually I was kind of surprised as what they did was talk me through it and upskill me with how to deal with the situation which was really helpful, I would ask them again for help* (Professional/CF 01).

A different side to this indicated a limited relationship between Cystic Fibrosis and palliative care services. The Cystic Fibrosis professionals reported that they would not ask nurses and doctors to contact the palliative care team out of hours for fear that the wrong advice would be offered. This was mainly due to concerns that treatment might be stopped or that inappropriate advice would be offered by a Palliative care service who might think the patient was dying. One of the professionals clarifies this below.

*That is always our advice when it comes to that (advice overnight). So being told to refer to Marie Curie where they wouldn’t necessarily give the right advice, because we continue our IVs until their last breath and they don’t do that* (Professional/CF 06).
A further Cystic Fibrosis professional recognised that they did not have a personal issue with the palliative care team they simply did not need to have a relationship with them.

_We don’t really have much to do with the palliative care team so haven’t really established any relationships with them. It’s not personal though. We only get them in when we really need them for our patients, not often (Professional/CF 07)._

For the patients who had experienced palliative care they recognised the importance of having their involvement and seeing them on a regular basis. The following two extracts were from patients who had been referred to the service for symptom control that illustrated how the integration can occur within the team alongside active treatment.

_I think palliative care have been really helpful, this time they have changed my meds but they always say they are going to run it by the CF team before they change anything to make sure it’s ok with the bosses and doesn’t make anything worse with all the antibiotics. They don’t interfere with anything else but it does help when they sort out my pain when I’m having physio (Patient 06)._

_The sickness has been awful this time with the antibiotics but palliative care have waved their magic wand actually I think they just help me feel relaxed and safe that someone will keep trying whilst I go through these wretched times and feel rubbish. It’s really good when you come in and you know the CF team will get in touch with them to pop in (Patient 03)._

The relationships between patients with Cystic Fibrosis and their health care professionals are clearly important. Patients in this study recognised that knowing people earlier in their disease trajectory is important for ongoing care which will be significant in service provision of Palliative care to patients with Cystic Fibrosis.
6.9.1.3. The “fit” of Palliative care within the Speciality of Cystic Fibrosis

Where the teams had worked together there was recognition that when palliative care was involved the Cystic Fibrosis team had found this beneficial and supportive. An integrated approach between palliative care and other specialities and in particular Cystic Fibrosis has been recognised as a model of care to take forward (Bourke et al. 2009; Quill & Abernethy 2013). One of the professionals indicated that having the palliative care team around to support the junior doctors in prescribing medications to help with symptoms can be very helpful.

*It is getting easier, I guess, nowadays, because we know we can straightaway involve the CF doctors if we feel it’s needed, if the medical team is feeling that this patient is struggling. So I feel it’s good in a way because the medical team sometimes have problems writing the treatment and they’re not really sure of how much and what they can give. Whereas the palliative care team come and they know exactly what is involved (Professional/CF 08).*

Five of the eight professionals felt strongly that palliative care could offer help with the symptom burden of the patients and to be reviewed at an earlier time point they felt would help with this, one of the professionals summed this up in the following extract.

*And you can get emm maybe members of the team that think that that person’s not going to make it and those who do which is why it’s like what you’re saying palliative care needs to be involved earlier because there’s people admitted with the symptom load they do or end up in such distress and if Palliative care is involved earlier then I think their experience would be amazing to be able to help guide us and then like work more as a team to identify where the patients are going (Professional/CF 01).*

The value of the contribution that palliative care could make to support Cystic
Fibrosis teams was recognised by some professionals but not all. Some of the working seemed historical and both teams sounded like they would consider looking at different ways of working. An interesting point by Fonseca suggests that when people are thought of as part of the system, they are governed by rules of the system and their actions result in it being difficult to consider different ways of working within the organisation (Fonseca 2002). This alone can challenge professionals in considering different ways of working and inhibit integrated working.

Four of the participants spoke about how special the Cystic Fibrosis team were and described this as eliteness although felt uncomfortable using this term. Three of the participants identified this through the hesitance in their voice when discussing this. This was not described as a personal issue in fact the palliative care professionals had respect for the job that the Cystic Fibrosis team do. Two of the professionals summarised this below.

*But I think if you sort of start to encroach on their speciality, they feel a little bit threatened. And I think they want to maintain, I don’t want to use the words, ‘eliteness’ but I think specialness! They’re quite isolated and choose to keep themselves isolated. I’m not saying that they should take their hope away, absolutely not, but I think something, they can be a little bit unrealistic. And I think, rather than the patients reaching a crisis, or coming in and everything seems to happen so quickly, I think if we were involved earlier then...I think that probably protecting their role because they are so specialised, and obviously if you let people in to view that role and to view how things are managed, then that’s when people start questioning your practice. I think they might feel that they will lose some control of those patients, and the relationship might not be as good as it was* (Professional/PC 04)

*It’s just that, you know, ‘we can do it. You know, we’ve coped with them so far, we want to support them until they die.’ ‘palliative care doesn’t have an understanding of our disease group.’ You know, that our disease group is very special because of this, this and that. And they don’t appreciate that* (Professional/CF 09).
The patients identified that palliative care should be part of the team and integrated as the other disciplines are. This thought was indicated by all of the patients except one who was unsure. Two of the patients below captured this in the extracts below.

*I think they should just be like the physios and others, just normal CF team. The doctors come and go all the time so we get used to that so we don’t need to see the palliative care team all the time but they should be part of the team (Patient 05).*

*Meeting people when you are sick is rubbish I’m happy to meet the palliative care team anytime at least knowing them when you’re well would be good. I guess we depend on the CF team to let us know when we should say them maybe that’s not right (Patient 03).*

There appeared to be a sense of teams not working together. In some instances the Cystic Fibrosis team seemed hesitant to include palliative care in case they took over the patient’s care, or offered advice that would not be supported by the Cystic Fibrosis team. The concept of teams working together is not new. Cancer and palliative care have learned to work together for the benefit of the patient as have other non-malignant groups such as cardiology (Caring together Programme 2010). From an organisational perspective any change has to consider where the demand is coming from; this could be from the demand side or changes on the supply side (Fonseca 2002). There may be resource issues that will affect innovation in Cystic Fibrosis and palliative care teams working together and this will be explored further within the discussion chapter. The following section will consider the final theme that relates to constantly redefining the future. In this section patients only referred to the sub category of affirmation from external sources regarding their
6.10. Theme 3: Constantly Redefining the Future

The final theme that has been generated relates to the patients constantly redefining their future and staff acknowledging that this happens. It is recognised that patients with Cystic Fibrosis face an uncertain disease trajectory and they are constantly redefining their future which indicates that palliative care needs to consider offering services to this group of patients in a different way (Jessup & Parkinson 2009).

The theme of constantly redefining the future was informed by the category of reality bites and sub categories of affirmation of life and death from external sources and trying to live a life when well. The sub category of affirmation from external sources relates to patients only. The theme, category and sub categories are illustrated in Table 26 below.

Table 26. Theme 3, Category and Subcategories

<table>
<thead>
<tr>
<th>Theme</th>
<th>Category</th>
<th>Sub Category</th>
</tr>
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<tbody>
<tr>
<td>Constantly redefining the future</td>
<td>“Reality Bites”</td>
<td>Affirmation from external sources that death will occur young (patients only)</td>
</tr>
<tr>
<td></td>
<td>Refers to patients and health care professionals recognising how limited the patient’s life might be and how that can happen unexpectedly</td>
<td>Patients with Cystic Fibrosis living normally when well</td>
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6.10.1 Reality Bites

Patients discussed throughout the interviews trying to live a normal life when
they were feeling well and how they did not always want to be reminded of the possibility of dying young. Health Care professionals also discussed that they recognised how patients live well when they can but that this can change quickly with an exacerbation of infection. The patients also discussed how their lives can change from one day to the next if an infection occurs. This is an important issue to consider in developing models of care as the currently the delivery of palliative care services which is determined by prognosis could be viewed as a barrier to referrals for this group.

6.10.1.1. Affirmation from External Sources of Seriousness of Illness.

The patients reported how when growing up there were constant reminders of their own mortality and how that made them feel growing up. One of the patients recounted hearing about a Cystic Fibrosis charity appeal on a children’s television show and how they discussed life expectancy and she spoke of how she felt her privacy had been intruded upon as her peers would have probably watched the programme.

And then like on Blue Peter, when we were little, when I was ten or eleven, they had this CF, they do this charity appeal, and CF was the charity. So again like all my peers would have watched that and they knew my life expectancy then. And I just, I don’t know, maybe it was me, but other people I’ve spoken to have kind of said, do you have like a number at the back of your head, and very aware of your life will be shorter and what you do now could affect that, I was feeling well at the time and then got a chest infection and boof you hear that (Patient 07).

One of the patients remembered being at school when a teenager and hearing about people with Cystic Fibrosis in a Biology lesson. She recounted hearing that she was likely to die young and how some years on she hoped that things
might be changing in view of the fact that patients with Cystic Fibrosis are living longer although with uncertainty.

*I think, hopefully it’s changing now, but people of my generation with CF are so well, that life expectancy is unbelievable. They’re like, yes when we were sixteen, we had to study it in Biology at school, and they tell the whole class that your life expectancy is thirty-two. I think I was only fifteen all my peers were there, I know the future is still uncertain but it is looking better but it doesn’t mean we don’t need help with symptoms when they are bad we just don’t want to talk about death all the time, I don’t really think about it when I’m well.* (Patient 04).

A further patient also alluded to how a charity that supports Cystic Fibrosis also reminded them of their limited life span and whilst she acknowledged why they have to do this it is a constant reminder for her of her mortality and something that she wished she could get away from.

*Oh okay. And I think, I mean I know why they do it, because I used to be a fundraiser for the Teenage Cancer Trust. So I understand why the CF Trust talk about it so much, and I know what it is and they need money and so obviously they’ve go on about it. But like they’ve just released this campaign saying, ‘Oh we’ve got, the CF Trust is fifty years old, so they’re campaign is all around the fact that most people with CF don’t reach fifty.’ Great, thanks! That’s just what you want to wake up to on a Tuesday morning. So it’s sort of...a constant reminder from the outside so to speak* (Patient 08).

In the two extracts below, patients discussed that they felt families and professionals tried to protect them but that they all knew the potential outcome of what their future might hold based on what was said from school age through to becoming an adult and how being with people who knew them and their disease was important in trying to live a normal life. One of the patients (Patient 02) became quite tearful when she spoke demonstrating how
emotional she felt about not being the same and the importance of being seen to be like everyone else.

*I know my mum and dad and my siblings all try to protect me but when you’re at school I was kind of on my own (eyes well up with tears), I didn’t tell my family too much of what was said but kids can be quite hurtful sometimes, truthful but, yeah hurtful there was no doubt I knew I wasn’t like the other kids (Patient 02).*

*When I went to high school I met some really good friends who, it’s kind of good cos you didn’t have to keep explaining what was wrong with you, likewise through university and because we are all living longer, marriage and kids and things, normal things are options (Patient 06)*

Patients acknowledged that at times there were sources of frustration in reminding them of their life expectancy and prognosis. This again is important to consider in the planning of introducing palliative care if the connotation is with death and dying as this may inhibit patients accepting being referred to palliative care.

### 6.10.1.2. Patients with Cystic Fibrosis Living a Life When Well

Both patients and staff acknowledged that when feeling well the Patients with Cystic Fibrosis try and retain as normal lifestyles as possible. The following professional extract recognised that patients would not want to talk about dying if they were well.

*Very very difficult because when the CF patients are well they just want to live life they want to go out get married have a job and they want to be here (hospital) as little time as possible and they definitely don’t want to talk about dying, so wouldn’t want to be seeing palliative care but things can change for them quite quickly (Professional/CF 01).*
One of the professionals indicated the difficulty supporting Patients with Cystic Fibrosis in the community when they are well as they will want to be independent. This supports challenges in determining when is a good time for the patients to meet palliative care both in and of the hospital setting and recognises that the way some services are set up are currently configured are not best suited to the needs of the patient.

I personally think, when patients are out in the community emm and they’re well with their CF they’re encouraging them to stay well and stay independent so I think then to link them in with CPCTeams (community palliative care teams) might give a bit of a mixed message because they want them to be functioning they want they to be independent and they want them to be going to work they want them to be going to college ye know they try they try and promote that emm so I think then linking in patients at that point is probably not good (Professional/PC 02).

One of the patients reflected on how she had been a relatively well patient but how she was now reflecting on her life and was considering how she felt being in hospital feeling relatively well but being aware that other patients were sick and thinking about when that would happen to her.

I was quite a well patient. But I do think it affected me. At the time I didn’t realise and I think now I’m evaluating my life recently, coming in to a hospital when you’re that age and you are relatively well and I had a job and I had a normal life and then suddenly you’re taken from that and you’re in a hospital environment for two weeks, which is quite a long time. And you see other patients that are poorly, that were quite sick. And it would actually make you question, ‘What’s going to happen to me?’ And you might not really ask people about it, but just seeing the people around you made you think, ‘I could be like that one day, I wonder what age it’s going to be when that happens to me.’ And it does make me think that there is the sort of things that doctors don’t realise when they’ve got a patient maybe that’s quite well (Patient 01).
Trying to live a normal life and be a mother was seen as being quite hard at times. One of the patients recognised how she tried to be as normal as possible but feels this is hard when she has to be admitted and leave her children behind.

At times I don’t really suffer at all. I go, what I see as normal with my friends, and I just suffer with my stomach, so I was taking Creon every day but my chest was fine. So I tried to not let it bother me. And then I started getting like a lot of chest infections when I was fourteen and the first one started with a... collapsed lung so I came in at the deep end. And I just sort of adjusted to what I had to adjust to. But it’s hard to have it with children, because it’s hard to explain to them why mummy’s ill and it’s harder to leave them. Even though they’ve grown up with it, they know, they knew...everything I never hide anything from them. Obviously I told them what they needed to know, for their ages (Patient 03).

One of the patients below also discussed how she has tried to be as normal as possible but had now acknowledged that she has had to consider not doing the things she used to do as she is limited by her breathing and sums up her thoughts when she says she has stopped dreaming about a happy ending.

Yes loads of stuff, it’s really, you know, I’ve had to sort of change direction.... I wouldn’t say its like stopped me doing, I wouldn’t say that, it would have stopped me trying. Yes, yes. And I’ve stopped dreaming about certain things, that kind of thing…happy endings, it’s good to talk (Patient 07).

Some of the professionals acknowledged how keeping the patients well was their utmost priority and how they would fight to ensure that they remained well.

And actually until they draw their last breath, we’re also fighting because they still want to go back home to their family, so they go back home, even though they are on the transplant list, they may still get the call, even if they know and we know that they know – they still want that kind of bit of hope. There’s
always hope that this is just another dip and not the end. And it’s always very
difficult for us to know. If this is just another dip or if it’s the dip that’s going to
be the end – so because we don’t ever know, is it fair to actually broach that in
case it’s not? (Professional/CF 08).

The ability to lead a normal life is important to this group of patients and is
encouraged by the professionals. Being able to do this and encouraging
independence is recognised as important in helping towards making decisions
about their ongoing care and treatment (Sands et al. 2011).

6.10.1.3. Summary of the Findings from all the Interviews
Within this chapter areas of organisational differences, language and
information that are used to inform patients of palliative care and time points to
consider a referral to palliative care have all been raised repeatedly as well as
the significance of relationships between patients and the Cystic Fibrosis
team. The key issues of the interviews are;

- The definitions and understanding of the term palliative care and the language
  used to describe it
- Integrated Care and relationships between patients and the specialist teams
- Access and barriers of referrals to palliative care and organisational influences
- Patient contribution to the development of services

From these issues theory is emerging relating to the needs and understanding
of the patients and professionals regarding palliative care and how
relationships can be fostered between teams involved in the care of the
patient with Cystic Fibrosis. The constraints of developing a more integrated
approach between services are also emerging with conceivable solutions. These issues will be further explored within the following discussion chapter.

6.11. Summary of Data from Phases 1, 2 and 3

Each phase of this study has contributed towards answering the research questions and has allowed the researcher to see the research topic from different perspectives from both patients and health care professionals. In phase 1 of the study the perceptions and previous experiences of professionals from both Cystic Fibrosis and palliative care were established. This demonstrated the challenges the teams face in using the term palliative care because of its connotation with death and dying. The teams also discussed the challenges of knowing when to refer to palliative care as there were no distinct guidelines. This was verbalised by both Cystic Fibrosis and palliative care teams. Interestingly the complex language used to describe palliative care was highlighted in all three phases within the study from both patients and professionals thus recognising the confusion that exists surrounding this area. A lack of clarity in knowing when to refer patients with Cystic Fibrosis to palliative care teams was also acknowledged by professionals within all phases of the study. Barriers of referrals to palliative care were also identified in all three phases alongside the identification of limited integration. The significance of relationships was highlighted in phase three of the study only. This particularly related to patients and their views on their need to know the teams who could be involved in their care. They identified that information relating to palliative care services would be helpful
and should be available at time points such as their annual review. In phase three only, the patients discussed how they were often made aware of their life limiting illness from external sources. They discussed television, radio programmes and school where Cystic Fibrosis was discussed and how that made them feel in front of their peers. The commonalities in all three phases of the study and findings that were present from phases two and three only are illustrated in Table 27 below.

<table>
<thead>
<tr>
<th>Commonalities in all 3 phases of the study</th>
<th>Phase 2 only</th>
<th>Phase 3 only</th>
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<tbody>
<tr>
<td>Perceptions and understanding of palliative care</td>
<td>Early referral to palliative care not seen as important</td>
<td>The significance of relationships for patients with teams</td>
</tr>
<tr>
<td>Barriers and enablers of referral to palliative care</td>
<td></td>
<td>The influence of external sources on patients as a reminder they are living with a life limiting illness (patients only)</td>
</tr>
<tr>
<td>Lack of clarity regarding when to refer to palliative care</td>
<td></td>
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<tr>
<td>Terminology/language of palliative care</td>
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<td>Limited integration</td>
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CHAPTER 7: DISCUSSION

7.1. Introduction

The findings from the study have demonstrated that integrating the specialities of Cystic Fibrosis and palliative care comes with challenges. The number of patients with Cystic Fibrosis is relatively small as indicated in Chapter 2, however, the identified symptom burden need of patients identified in Chapter 3 and the information gathered in the data collection has demonstrated limitations in the development of integrated services between the two specialities. The data have demonstrated a lack of understanding regarding palliative care from both professionals and patients, a lack of clarity regarding when to refer to the palliative care service, and has also highlighted patient’s needs with regards to the development of relationships.

This chapter will offer a discussion related to the information that has emerged from the data analysis. This will include perspectives of palliative care, including the name and the meaning attached to this. Considerations in reconfiguring services and the involvement of the patient will be discussed followed by integrated working and the significance of relationships between patients and health care professional teams. Organisational influences affecting hospital Trusts will also be considered. A unique integrated model of care that has emerged from the data will be proposed for use in patients with Cystic Fibrosis when considering the involvement of palliative care. Implications for practice and future research recommendations will also be discussed. The research aim and research questions are reiterated below.
Research Aim and Questions

<table>
<thead>
<tr>
<th>Research Aim</th>
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<tr>
<td>1. To explore the experiences and perceptions of patients with Cystic Fibrosis and staff regarding palliative care and the acceptability of this as a service early in the patient’s disease trajectory.</td>
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<table>
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<th>Research Questions</th>
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<tbody>
<tr>
<td>1. What are patients with Cystic Fibrosis and health care professionals’ experiences and perceptions of palliative care?</td>
</tr>
<tr>
<td>2. What are the barriers and facilitators of a palliative care referral in Cystic Fibrosis?</td>
</tr>
<tr>
<td>3. Are the services for the provision of palliative care within Cystic Fibrosis integrated as part of an multi-disciplinary team</td>
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</table>

7.2. Information Gathered Through Mixed Methods and Inference to the Research Questions

As recognised in Chapter 4 the data analysis for the exploratory sequential design study followed recommendations as suggested by Creswell & Plano Clark (2011). It is recommended that in considering connected results the researcher considers drawing conclusions from the mixed methods. In the exploratory sequential design applied to this study the researcher considered how each method had contributed in answering the research questions (Creswell & Plano Clark 2011). This is illustrated below in Figure 8.

The Focus Group highlighted the perceptions and experiences professionals had with the name palliative care and what it meant. They spoke of how they changed the name of the palliative care team when talking to patients. The issue of knowing when to refer to palliative care was also raised. The Focus Group identified important issues and from this helped in constructing questions to be asked throughout the survey which helped identify if the perceptions raised in the focus group were generalised. The focus group did
answer only part of research question 1 as patients were not part of this Focus Group.

Figure 8 How each method contributed to answering the research question.

The survey identified from the respondents the size of the problem and demonstrated that the issues raised in the focus group were also being illustrated in other areas of the United Kingdom. The survey confirmed other teams do not know when to refer to palliative care and many teams do not have an integrated approach to care. Figure 9 below illustrates an example of how the issue of knowing when to refer to palliative care was connected through the three methods applied. Lack of clarity regarding when to refer patients with Cystic Fibrosis to palliative care was raised in all three phases of the study and findings from this research can support defining a more integrated approach to care.
The application of mixed methods research gave a comprehensive view of the findings from original data and resulted in a more generalised understanding of the issues established and offered the opportunity to see perspectives through differing lenses.

7.3. Perspectives of Palliative care

Alongside the finding of palliative care being introduced by professionals as a symptom control team, patients felt when they met palliative care it had been viewed as a last resort. It is difficult to determine why palliative care is viewed in this way. One reason is the meaning attributed to Palliative care regarding the connection with death and dying. When palliative care reviewed patients with Cystic Fibrosis, the patients did expect the palliative care team to help with symptom control. This was highlighted with Patients 06 and 07 who were referred for pain and nausea. Whilst this research was not to examine end of life care in patients with Cystic Fibrosis, they do have a life limiting illness therefore seeing patients for symptom control before the patients are entering the dying phase allows for a rapport between patients and professionals to be
established. This can help if patients deteriorate and need end of life care (Dalal et al. 2011). From the interviews, patients (06 and 08) spoke of feeling so desperate to feel better that they did not care what the palliative care team was called.

Within the literature it is recognised in the cancer population how palliative care might be introduced to patients. Oncologists recognise that they suggest the patient meeting the palliative care team so they can get to know them when they are feeling well and can establish a relationship with them rather than waiting until they are too sick to benefit from meeting the team (Broom et al. 2013). Similarities between this study and the findings from the researcher's study are evident. Patients with Cystic Fibrosis want a relationship with health care professionals involved in their care including the palliative care team. Patients want care to feel personalised and not to be viewed as a statistic.

Various approaches of manipulating the meaning associated with palliative care have been considered. One suggestion about “getting around the problem” is by not getting entrenched in the name of what the service is called. The “getting over it” approach considers continuing to demystify the hidden meaning of palliative care (Meier 2005; Cherny 2009). This has in the last few years been endorsed in the cancer population through the American Society of Clinical Oncology releasing a new statement endorsing the WHO definition (2002) which confirms palliative care being applicable throughout a patient’s illness and continuing through active treatments. Ultimately all of
these versions relate to palliative care but describe it in an acceptable way for professionals and patients.

Whilst it is clear that palliative care has developed from within the cancer model, there remains evidence more than two decades on that referral pathways for palliative care in cancer remain unclear and at times ambiguous with changes being made to names of services and various definitions underpinning what palliative care is about (Doyle 2003; Cherny 2009; Melvin 2010; Dalal 2011). It would appear that professionals have transferred a less than perfect model of care to a population with non-malignant disease that has created even more confusion around definitions of palliative care and in determining when a referral to palliative care should occur. If referral to palliative care is to be based on need rather than disease or extent of disease then different models of care must be established for patients with non-malignant disease, in particular within the context of this study. Fundamentally palliative care services should be responsive to individual patient needs. Due consideration must be given to the referrers knowledge and beliefs about the speciality and if they perceive palliative care is about death and dying then palliative care services should consider a name change. Alternatively education and training within organisations related to the WHO (2002) palliative care definition could be offered with teaching punctuated by clinical scenarios of care that have demonstrated the benefits early palliative care can offer.
7.4. Considerations for Designing Services and Patient Involvement

Confusion around terminology used in palliative care and professionals knowing when to consider a referral to the service are all limiting factors in the referral process and access to services. This was highlighted in all three phases of the study. Participants disclosed how they refer to palliative care as “symptom control” and others described throughout the findings the difficulty in knowing when to refer to palliative care. Based on the needs of the patients with Cystic Fibrosis a referral to palliative care earlier in the disease trajectory may help in reducing symptom burden and improve quality of life as in other disease groups (Sawicki et al. 2008; Dellon et al. 2010; Temel et al. 2010).

Definitions can be important as they can influence how palliative care is practiced and to whom palliative care is offered (Pastrana et al. 2008). In the United States the name palliative care was seen as a barrier of referrals to palliative care as the oncologists felt it reduced hope for patients (Dalal et al. 2011). This was felt to be one of the main reasons for a lack of early referral to an established palliative care service. The name was changed to supportive care that resulted in an increase in appropriate referrals with an overall increase in patient referrals of 41% (Dalal et al. 2011). The findings of the Dalal et al.’s (2011) study are important within the context of this study as the term palliative care and the meaning of it held professional and personal significance for both patients and staff. It is acclaimed that without clear understanding of what palliative care is, people will reflect upon previous experience of palliative care with friends or families (Maciasz 2013).
The involvement of patients in the redesigning of services is well established in current policy (Kings Fund 2013; Health Foundation 2014). It is evident that patients with Cystic Fibrosis are not as involved in their care as they would prefer. However when patients do become involved, health care decisions are improved, outcomes improve and importantly for this study, resources are allocated more efficiently (Kings Fund 2014). Patient involvement coheres with establishing integrated services between Cystic Fibrosis and palliative care. The voice of patients and integrated services have been viewed by policy makers as two major connecting priorities in developing future services which resonates with the results of this study in the planning of future services (Kings Fund 2014).

The issue of considering patient experience and participation in their care is important in considering palliative care involvement. Currently patients with Cystic Fibrosis are unable to make an informed choice about access to this service as in the main they are unaware that this service exists to support them early in their disease journey and not just as they approach death.

Patients recognised that they were unsure about what palliative care services could offer them and stated that having information available would help them understand the service (Patients 02, 03, and 04). The “symptom control team” was a phrase alluded to by participants in the Focus Group and the interviews and was identified in the survey as being one of the main triggers for referral to palliative care. Interestingly within the literature this term is not recognised within the systematic review looking at terminology used to describe palliative
care (Hui et al. 2013). When patients were asked about the term symptom control they felt it described better what the team were coming to provide but also felt that if the term palliative care was used, that was acceptable as long as they were made aware of what it was about and not just about end of life care.

This research has recognised that patients are requesting more information regarding palliative care services and access to information. This information is currently limited or not available. In order to support the patient in making informed choices Piper (2014) suggested applying four indicators which included a shift in power from professionals to the patient, informed individual choice, individual patient control over decision making and two way professional patient partnership working. As indicated in this study patients were cognisant of the lack of information pertaining to palliative care.

Working to support patient empowerment would offer patients with Cystic Fibrosis the right to participate in considering informed choices and to consider referral to palliative care when they felt it was appropriate. Previous evidence has suggested that self-management education has improved knowledge of Cystic Fibrosis and its management for patients and carers (Savage et al. 2014). This concurs with the current study that patients having better knowledge of palliative care may help in patients initiating discussions regarding palliative care with health care professionals.

In contrast to this professionals are advised to carefully consider supporting patient involvement and be mindful of the fact that patients may not have the
skills to make informed choices and decisions regarding which services to access and when to activate them (Bradshaw 2008). The literature affirms that patient choice is influenced by a number of antecedents including a wider personal agenda for the patient, life context, financial issues and spiritual and cultural beliefs (Piper 2009; Anderson & Funnell 2010). Patient choice in relation to palliative care has in the past focused primarily on issues relating to end of life care. The emphasis for the speciality in the last six years has focused on patient choice regarding their preferred place of care and death and whether these preferences have been achieved (DH 2008; Oxenham et al. 2013). Enhancing the experience of patients with Cystic Fibrosis would mean supporting them with information ensuring they were aware of the service much earlier in their disease journey. Promoting the integration of palliative care services and knowing who the team were and how to contact them are pivotal in meeting the needs of the patients. Information regarding the service would need to include appropriate timelines for referral to guide the patient.

In the patient interviews the findings highlighted patient self-referral to the palliative care service was discussed. Historically hospital palliative care services have not encouraged patient self-referrals to the service (Dunlop & Hockley 1998). This has predominantly been based on the hospital palliative care services originating as advisory teams only and out of professional respect have always requested approval from the primary team to become involved in the patient’s care (Dunlop & Hockley 1998).
The issue of inviting patient views should be encouraged however the overarching issue of resources and financial constraints within the NHS cannot be overlooked. Although resources and financial constraints did not emerge from the data as barriers of referral to palliative care, they do ultimately underpin the configuration of services. The solution for meeting the needs of the patients and to prevent a further drain on resources lies in a more integrated model of delivering care from a palliative care service that reviews patients intermittently based on need rather than stage of disease.

7.5 Integrated Working

This section will explore integrated working between teams to support referrals to palliative care services in the hospital. The impact of the relationships between specialists and the relationship between the health care professional and the patient will also be considered.

7.5.1 Integrated Working between Specialists

There are several models of care alluded to in the literature relating to services working towards integrated models of care (Krause et al. 2006; Selman et al. 2007; Bourke et al. 2009; Disler et al. 2013). In the cancer literature it is still believed that patients continue to be referred to palliative care services too late and that different models of integrated care need to be developed (Bruera & Hui 2010). From this research project it was evident that integrated models of working are limited between Cystic Fibrosis and palliative care and that development of new ways of working are needed to support patients earlier in the disease trajectory (Bourke et al. 2009).
It is imperative that palliative care specialists and the leading clinician for the patient promote joint working between the teams to meet patient needs (APM 2012). A lack of coordination of care amongst professionals from differing specialities has also been cited as a reason for patients not expressing their needs which can lead to a delay in palliative care being considered as part of their care (Mahtani & Chugani 2010). The principles of integrated working can be considered across many differing boundaries, namely, organisational and/or team practices. Integrated working aims to encourage people to work collectively to meet the needs of the patients. The need to review established working patterns between teams is useful. However, creating new service arrangements may disrupt some well established relationships or question areas where a lack of relationship is established. In the latter circumstance priority should be given to the establishment of new networks and relationships to enhance patient care and possibly influence commissioning strategies (Skills for Care 2014).

Integrated working of the Cystic Fibrosis team with other teams out with the core MDT will be for some a completely different way of working. In order to gain a rapport within Cystic Fibrosis and palliative care teams, some teams have developed a service where patients are seen under a joint review (Boland et al. 2013); this not only supports the patient seeing the teams working together but allows a trusting relationship to build between the Cystic Fibrosis and palliative care specialists. This type of service is currently offered in the minority of services based on the current research findings.
Bourke *et al.* (2009) determined from a retrospective note review that an integrated model of care provision should be offered to patients with Cystic Fibrosis. This should be established when the Cystic Fibrosis team feel this is necessary and suggested that palliative care and Cystic Fibrosis teams should work together when patients’ disease is advanced and active therapies are coming to an end. This model could perhaps be challenged in that whilst palliative care specialists are not expert in the management of Cystic Fibrosis, they do have a responsibility to ensure Cystic Fibrosis professionals are equipped to offer modern day palliative care and may not consider earlier referral to the service. Relationships with Palliative care teams and other specialists have been alluded to in previous research (*Broome et al.* 2012). The evidence states that if palliative care clinicians are readily available and visible then timely referrals are more likely to occur (*Broom et al.* 2012).

From the findings of the current research project patients want more than being referred to palliative care when the Cystic Fibrosis team are ready. The patients require a relationship with the Palliative care team earlier in their disease journey and want to feel that they know the professionals whom will be caring for them. This will be further discussed later in this section. An integrated team is more than a number of health care professionals coming together; it is one that comes together with members using open and honest communication based on mutual respect and trust which for many teams will take time in establishing new innovative working relationships (*Skills for Care* 2014). Within Cystic Fibrosis and palliative care for some teams there is no or
limited existing relationships so this model of care would be innovative for some services.

Within this study there was evidence of respect between palliative care and Cystic Fibrosis teams. However, this was limited in numbers as only a small number of respondents described a fully integrated model of care. In many chronic conditions professionals have known patients and their families over many years. This is also true of patients with Cystic Fibrosis. Professionals working within Cystic Fibrosis acknowledged that they felt they knew the patient the best and verbalised that they felt they could meet their needs. Although not expressed in all interviews with professionals there was concern that when palliative care was involved active treatment would need to stop. In developing new models of care patients with non-curable lung disease should be able to access palliative care services on an as required basis with the primary team remaining the clinical lead for the patient. This would mean patients being reviewed for short periods of time for a particular symptom and then not accessing the service again for months even years (Boland et al. 2013). This would have a three-fold benefit. Firstly the patient has additional access to specialist symptom control advice, the Cystic Fibrosis professionals have access to specialist advice and thirdly the patient has the opportunity to meet the palliative care team with whom they can begin to build a rapport with.

7.5.2. Multidisciplinary Team Working

There are many published benefits of multi-disciplinary team working with recognised benefits in decision making in patient care as well as notably
having a positive impact on the numbers of differing decisions being made by independent practitioners (Pfeiffer & Naglieri 1983; Sim & Joyner 2002; MNDA 2011). A further study identified that as a result of the integration of services from within an MDT there had been substantial improvements in the physical and psychological well-being of patients dealing with multiple chronic illnesses (Krause et al. 2006). Within the speciality of cancer care, palliative care is recognised in peer review standards as a key member of most cancer specific multidisciplinary team meetings that occur in the acute setting. In order to meet the needs of these services there is usually shared responsibility between team members to ensure palliative care is represented at these meetings. When resources are limited there is often negotiation between the teams to discuss the current joint patients at the beginning of meetings or to discuss patients that the cancer teams are concerned about and need consideration of referral to palliative care. This method of attendance at multidisciplinary team has been established over the last two decades. Involvement of Palliative care within non-malignant multi-disciplinary teams is still in the early stages of development, in Cystic Fibrosis there are pockets of teams where palliative care is included within their multidisciplinary team meeting.

Whilst increasing communication between the specialists is an added benefit of palliative care teams attending the Cystic Fibrosis multi-disciplinary team the opportunity of shared learning between the teams can also be realised (Ruhstaller et al. 2006). Shared learning within the multi-disciplinary team may allow for new referrals to palliative care to be discussed and a better
understanding of the Cystic Fibrosis disease and treatments available may lead to enhanced integrated working.

7.5.3 The Significance of Patient/Professional Relationships

In palliative care it is recognised through literature the benefits of having a therapeutic relationship between the patient and the professional (Luker et al. 2000; Kennedy 2005). Part of establishing a good relationship with patients and families relates to being able to best support patients and families when they enter the end of life phase (Kennedy 2005).

Nurses have recognised that knowing a patient who has a life limiting illness earlier in their disease trajectory allows for the building of relationships between the patient and the family with the health care professional and allows trust to be fostered (Tomison & McDowell 2011). This study also indicated that for the patients building a relationship with professionals was important. Within the interviews all the patients with Cystic Fibrosis alluded to the importance of having a therapeutic relationship with the teams looking after them. They actively stated that they would not want to be seen by a team that was unknown to them when they were dying. Tomison & MacDowell (2011) also established that patients with non-malignant conditions were much less likely to be referred early to palliative care and that the first meeting of the patient and family was usually at a crisis point when patients were distressed and families were frightened. Interestingly not all relationships between health care professionals and patients require longevity. Hill et al. (2014) recognised that psycho-social support could be delivered on the first meeting with a
patient and did not require an established professional patient relationship. However patients with Cystic Fibrosis have established relationships with most of the core multi-disciplinary team throughout their illness and it is understandable that they want some kind of relationship with palliative care.

Patients with Cystic Fibrosis have an established relationship with the health care professionals caring for them. The care they receive may be as an in-patient requiring treatment for an exacerbation episode or may be as an out-patient for a regular review. Patients with Cystic Fibrosis state that when they come and see the Cystic Fibrosis team they feel similar to seeing “the family” so strong is the relationship. From a health care professional perspective the team deliver specialised care but running alongside this they observe patients reach milestones of university, relationships, marriage and pregnancies. For others as the patient’s disease progress they observe the patient reverting back into child mode and observe parents/family rediscovering the caring role. With the relationship between the patient and the Cystic Fibrosis team being well established trying to introduce a different team (palliative care) not seen as part of the core Cystic Fibrosis team will more than likely be unsuccessful unless the palliative care team is endorsed by the Cystic Fibrosis team. This would involve acknowledging the palliative care team as established members of the Cystic Fibrosis team.

Recommendations to demonstrate palliative care involvement could be firstly information booklets, either stand-alone palliative care booklets but specifically written for Patients with Cystic Fibrosis and their families explaining what the
palliative care team is with an emphasis on early referral for symptom control, for symptoms such as antibiotic induced nausea. Secondly being visible on the wards with the Cystic Fibrosis team seeing patients together will help establish closer links between the teams and the patients. Even if there are no shared patients between the two teams, staff will become used to seeing the palliative care team on the wards and will begin to recognise who they are and what the service can offer. This would hopefully result in the palliative care team being seen as an integrated member of the Cystic Fibrosis team and encourage referrals by staff and reassure patients. Most hospital wards have team member photograph boards visible for patients and staff so they know who core team members are. It was recognised from the findings of this study that even when a palliative care service is viewed as being an extended member of the Cystic Fibrosis team they were not recognised on the picture board or in the literature. Having an identified palliative care team link with representation on photograph boards may also affect relationships between staff and patients as well as confirm for staff who to call if a referral needs to be made. Some of these recommendations may seem simplistic but these are strategies that will help establish palliative care becoming more integrated within Cystic Fibrosis teams.

Resources may be a consideration in meeting the needs of the Cystic Fibrosis team but information booklets could be available with other patient information leaflets and it has been established previously in this thesis that attendance at the full MDT may be required in the short term only until relationships are established. Patients with Cystic Fibrosis clearly want to know who the
palliative care team are, what the service offers and want to feel like they know the team and have an established link with them which is not something that has been recognised previously.

Whilst integrated working has been identified as a way forward for Cystic Fibrosis specialists and palliative care teams this ethos may be a step too far for teams where there is a limited or no relationship between Cystic Fibrosis and palliative care. Setting triggers for referral may guide referrers to palliative care in order that teams can build relationships with one another. There is a need for palliative care to be seen as part of the existing Cystic Fibrosis team as reported by patients interviewed in this study.

7.6. Organisational Influences in the Integration of Cystic Fibrosis and Palliative care

The following section will discuss the organisational influences in the place of palliative care within the Hospital. Consideration will be given to organisational influences that impact on Palliative care services in the hospital Trusts and inform integrated working. Influencing factors such as funding of palliative care and the culture of the organisation towards palliative care will be addressed.

7.6.1 Financial Influences Affecting Interpretation of Palliative care

From a Government perspective there is a commitment to funding Palliative care but currently there is still no agreed mechanism for funding it in the UK. Much of palliative and end of life care is provided by hospices based in the
voluntary sector. The level of statutory funding they receive varies significantly and many hospices will run on donations, fundraising and legacies (National Council for palliative care 2011). Community palliative care services are in the main funded from Clinical Commissioning Groups (CCGs). Hospital palliative care teams are infrequently non-profit making teams as currently there is no tariff for palliative care services. More recently commissioners have rewarded healthcare providers by linking sums of money to local quality improvement measures and the achievement of such measures. Commissioning for Quality and Innovation (CQUIN) has been agreed by many providers across the UK to improve services. Many services across South East England have End of Life Care as one of these measures. The focus is on identifying patients who are entering the end of life phase with an emphasis on ensuring their preferences are acknowledged and where possible their preferred place of care and death achieved. The cost attached to each CQUIN varies but, end of life care is approximately worth between; £450,000 - £550,000 if the measures are achieved. Hospital palliative care teams are currently not paid for the service they provide and therefore generating significant monies as in the case of achieving a CQUIN is an incentive for both the team and the hospital Trust. The dichotomy here is with an emphasis and drive on monies linked with end of life care palliative care teams could be in a position of shifting their focus towards end of life care and therefore not seen to be promoting earlier referrals to their services. This has in turn supported the earlier views of palliative care as an end of life care service.
A further end of life care financial incentive has been around the Quality, Innovation, and Productivity and Prevention (QIPP) agenda. The aim of this has been to develop key performance indicators to improve the numbers of patients who die in their own home, a further end of life care initiative. The End of Life Care Strategy (DH 2008) was the first document to look at end of life care for all patients with a life limiting illnesses. With this strategy money was ring fenced for innovations in care, research and new work streams to be created. This strategy has been successful is ensuring end of life care has been brought to everyone’s attention but the unintended effect of this strategy has been palliative care once again being viewed as an end of life care service dictated to by funding and overriding strategies and changes in Government.

In 2010 the Government initiated an independent review of palliative care funding, interestingly to offer yet a further definition regarding what constitutes dedicated palliative care services and to propose a mechanism for funding such services (Hughes-Hallett 2011). A first draft of the suggested funding stream for palliative care services was published in November 2014 and it is clear that palliative care services will be paid based on the needs of the patients. It is important to consider funding issues and the implications of this upon Trusts. Innovative ways of working need to be founded on outcomes, for patients with non-malignant disease and in particularly those patients with Cystic Fibrosis early. These patients will die and therefore early palliative care can help support patients throughout their disease. The challenge for palliative care is in ensuring that it is not viewed solely as a provider of end of life care.
7.6.2. Culture of organisations

The cultural ethos of palliative care is seen as an influencing factor in the delivery and uptake of services with patient expectation viewed as having an impact on the make-up of palliative care services (Abernethy & Currow 2008).

In any organisational culture it is important to ascertain the place and perception of palliative care. In a cancer setting palliative care may be viewed as being important but would not want to highlight the service outcomes in case of affecting the way it is perceived by commissioners and the public which may be as a place of cure. The need for cultural change is invariably related to organisational performance (Scott et al. 2003). Changing culture within organisations is not easy but changing conversations can support staff to consider why they do what they do (Shaw 2002). Talking about the relationships between Cystic Fibrosis and palliative care will help the situation evolve; understanding locally what the teams want and what the patients need can help influence perceptions of teams working together at Trust Board level. Within the current study, the experts from the focus group acknowledged that they never meet in normal circumstances to have conversations about the way the teams work together. The focus group in itself, had inadvertently changed a conversation about the way teams work together within organisations that seemed to ignite other ideas for the experts to take forward within their own organisations.

The significance of changing cultures within organisations to embrace integrated care has been highlighted in health policy documents (Shaw et al. 2002).
2011; Kings Fund 2013). Within policy reference is made to ensuring hospital organisations pledge more immediate access to specialist advice for patients (Kings Fund 2013). It is known that patients circulate between organisations on their healthcare journey, and there is often inefficiency and waste that can create a poor experience (Skills for Care 2014). This is relevant in the researcher's study as the anticipated outcome of this work will encourage organisations to focus attention on how different services can work together to benefit patients. Any potential change to the culture of an organisation will challenge previous practices and historical ways of delivering care. For change to occur to support integrated working, the focus will need to relate to encouraging new relationships, a different power base and new ways to communicate (Shaw et al. 2011; Skills for Care 2014).

Innovation in hospitals will need to cross organisational boundaries and in doing so can pose threats to established groups than can in turn result in a degree of conflict (Fonseca 2002). This, along with a challenge to professionals' beliefs about an organisation, can result in "identity threats" that can be disruptive and have a negative impact on innovation which can impact on developing integrated care (Ravasi & Schultz 2006). There is evidence to support palliative care being involved with patients earlier (Temel et al. 2010; Stevens et al. 2014). Organisations would struggle to argue with this, however, they need the speciality of palliative care to be clear about what is on offer and how that can benefit the patient and increase revenue. There is no mandate to refer to Palliative care services other than those offering
monies for end of life care improvements. Hospital palliative care is dependent on specialists from areas such as Cystic Fibrosis referring patients to the service. In the event that patients self-refer to a palliative care team, permission from the primary treating team will always be ascertained. This is mainly due to support of any recommended changes to current medical management such as pharmacology.

Organisational learning may be able to help with knowledge and understanding about the place of palliative care within an organisation (Carroll & Edmondson 2002). Tensions between early referral and end of life care can be demystified through effective conversations which can be helpful towards establishing goals not just for palliative care but for the Trust as a whole (Carroll & Edmondson 2002).

With competing priorities for services there is a lack of recognition of palliative care contribution within organisations some of which may be related to a lack of visual representation regarding what defines a palliative care regardless of organisational position or culture.

7.7. Considerations for Future Palliative Care

The challenge for palliative care is in considering working in a different way to meet the needs of patients with Cystic Fibrosis. The current practice for referral to most palliative care teams is based on the prognosis of the patient. In most centres the last twelve months of life is seen as appropriate for a
referral to palliative care. However this can also be harnessed as end of life care therefore the language and the confusion around the terms relating to palliative care does not help patients with Cystic Fibrosis as prognosis is unpredictable and patients are denied access to services as a result of this.

Palliative care has to decide on whether it is a service as defined in the definition adopted within this study (WHO 2002) or an end of life care service. Introducing different models of care that are integrated will help balance the resources needed to meet the needs of these patients. Being involved with patients on a short term basis throughout periods of an exacerbation is one way of achieving this as well as getting to know the patient and family. An uncertain prognosis should not deny patients access to this service or occur so late that the patient or family have no relationship with the team.

7.8. Proposed Model of Integrated Care

The following section addresses how the results of this study and development of a theoretical model from these results can influence clinical practice. The findings from the literature review the findings and discussion have led to discernible issues that can change the way Cystic Fibrosis and palliative care Teams work together. Figure 10 below illustrates concepts to be considered in developing a theoretical model of integrated care and Figure 11 illustrates a theoretical model that has emerged through the findings of this study.
This theoretical model illustrated in Figure 11 represents the ways in which palliative care can be conceptualised within Cystic Fibrosis. This model is developed from the data generated from the focus group, the survey and the interviews. It challenges the current dialogue within the Cystic Fibrosis literature that equates palliative care being involved at the end of the patient’s life. It represents views from patients which have not been identified previously and which have highlighted the significance of relationship building with palliative care and of being made aware of what services can offer earlier in their disease. The model involves palliative care being viewed as part of the Cystic Fibrosis team but acknowledges that palliative care resources are not infinite and new ways of working need to evolve. The model highlights that having referral guidelines will help in recognising patients and demonstrates how the four segments of the model are integrated and inter-connected.

Whilst the model illustrates the way forward it also recognised the concepts to be considered before the model could be implemented. This information is taken from the data generated from the research. The findings from the research suggested that in some cases the professionals felt the patients with Cystic Fibrosis would be distressed by having palliative care mentioned. In most cases the patients did not express this; therefore this model challenges some of the mis-conceptions held by professionals and encourages specialist palliative care to at least have information about the service accessible to patients. This clarifies the importance of patients being involved in the planning and organisation of services and in listening to what their needs are.
The current view of palliative care among specialist Cystic Fibrosis health care professionals is one based on the association of death and dying and not on the needs of the patient as demonstrated in section 3.4 of the literature review. The existing literature elucidates the associated symptom burden of this group of patients and from the patient interviews it was identified that accessing palliative care to help with this was perceived to be a last resort. Being able to challenge the existing model of care through defining palliative care in a way that fits with the organisational culture and dispel the association of death and dying will help towards patients being able to access an integrated service between Cystic Fibrosis and palliative care.
Figure 10: Concepts to be considered to develop an Integrated Model of Care between Cystic Fibrosis and Palliative care Teams.

- **Organisational**
  - Lack of integrated care between hospital services and hospital and community

- **Palliative care**
  - Lack of CF understanding
  - Resources and financial links with end of life care

- **CF team issues**
  - PC associated with death and dying
  - Based on life expectancy not patient need

- **Patient issues**
  - Lack of information
  - Unsure about what Palliative care can offer
Figure 11: Proposed model of Integration between Cystic Fibrosis and Palliative Care based on results from research data

- Shared guidelines
- Short term intervention by hospital and community palliative care services

- Information
- Part of attendance at CF MDT

- Annual review
- Palliative care part of CF hospital team
- (picture boards and literature)

Create referral guidelines between CF and PC

Build Relationships between CF and PC teams

Develop information for patients to be accessed early in adult disease

Patient involvement

Develop language that suits the organisational culture and the patients

- Use the term symptom control if this feels easier to refer patients
7.9. Implications for Practice

This study has highlighted that patients with Cystic Fibrosis are living longer into adulthood but are living with a heavy symptom burden at different times in their disease (Stenekes et al. 2009). The role of palliative care is under researched in this area and research studies in the main have focused on end of life care (Mitchell et al. 2000; Chapman et al. 2005; Sawicki & Robinson 2008). The findings from this three-phase study have highlighted issues that need to be considered in future service provision between both Cystic Fibrosis and palliative care services.

The uncertainty regarding when to refer patients with Cystic Fibrosis to palliative care services was apparent in all three phases of the study from the health care professional participants. There is now a recognised need for both Cystic Fibrosis teams and palliative care teams to work together to define a set of triggers to support the referral pathway and a more integrated approach to care. Transplant, whilst identified in the findings as perhaps being too late for consideration of a referral to palliative care services, is a defined time point when referral to palliative care team should at least be considered. This study has highlighted that in all the adult specialist Cystic Fibrosis centres there is access to a hospital palliative care team. Communication between the two services need to be developed to find a more integrated way of working to support patients. The dissemination of the results of this study will help in presenting the viewpoints and needs of the patients which to date had not been represented.
The connotation of the meaning of language used to describe palliative care is important in considering implications for practice. This study has identified how professionals change the name of palliative care services to make it easier to raise the subject with patients and carers. This appears to be related to the connotation of palliative care and its association with death and dying.

In the literature relating to cancer treatment, there is now evidence that a change of name can influence professional referrals (Dalal 2011). This study has highlighted that some of the difficulty with the term, ‘palliative care’ relates to professionals’ concerns about it rather than patients’. Findings demonstrated that in the majority of cases patients were in agreement with being seen by a palliative care service as long as it was explained to them what palliative care could offer and why they were seeing the patient. At a fundamental level this could be addressed through education and training to professionals about palliative care and how best to refer to the introduction of this service. Palliative care should also be seen as integral to the multidisciplinary team where they could be part of patient information forums alongside the Cystic Fibrosis team. The literature has supported the fact that the name of the service is irrelevant unless it is preventing referral to the service.

Palliative care teams may need to consider a name change to make it clearer as to how to introduce their service to patients with Cystic Fibrosis which may increase referrals, as seen in the cancer population (Dalal 2011). Finally specialists from both Cystic Fibrosis and palliative care teams need to
consider the significance for the patients in being able to build a relationship with palliative care teams. This study did not specifically look at resources but it is recognised from the literature that different models of care need to be developed to meet the needs of patients (Quill & Abernethy 2013). Developing short term interventions for patients with Cystic Fibrosis may be helpful in establishing relationships with palliative care services, especially when patients experience uncontrolled symptoms. As the symptoms resolve, palliative care services would become less involved and return care solely to the Cystic Fibrosis team thus developing a more integrated approach to care.

The implementation of the proposed model for integration between the two services as presented on Figure 11 does not necessarily require additional resources. What it does need is for both Cystic Fibrosis and palliative care teams to consider working in a different way and applying a more integrated approach to care. Cystic Fibrosis teams should consider palliative care as an integral service to multidisciplinary working and palliative care teams should consider seeing patients on a short term intervention and then withdrawing from the patient’s care until needed in the future. This prevents a drain on resources and helps build a relationship with the patients and their families. The more strategic challenge for palliative care services is in redefining what their service can offer in terms of palliative and end of life care. Many teams are now focusing on end of life care due to financial implications as previously discussed in chapter 7 (section 7.6.1). The ethos of palliative care is to be receptive to the needs of patients at any time of their disease trajectory (WHO 2002). Coupled with the emphasis of palliative care on end of life care and the
confusion regarding the terminology being used to describe the service, require further consideration and attention for all palliative care services. Communication, between the two services, is key in the development of services. Whilst palliative care attendance for the whole multidisciplinary team meeting may not be possible, negotiation around discussing patients who may be of shared interest at either the beginning or the end of the meeting may be one way of building relationships between the teams without having a significant impact on resources. The data from the patients are explicit in describing the need for information regarding palliative care services which could be easily achieved through adding palliative care into existing patient information. This would, however, require some negotiation with Cystic Fibrosis teams in realising the needs of the patients in terms of understanding that palliative care is about more than death and dying. Below in Table 28 the implications for practice are summarised with potential solutions.

**Table 28. Summary of Implications for Practice**

<table>
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<th>Implication</th>
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<tr>
<td>Uncertainty of when to refer to palliative care</td>
<td>Development of triggers for referral to palliative care and shared guidelines</td>
</tr>
<tr>
<td>Language used to describe palliative care</td>
<td>Consider changing the name of palliative care to a term better understood and easy to understand for patients such as “symptom control team”</td>
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<tr>
<td>Building of relationships</td>
<td>Introduce palliative care as an integral part of the Cystic Fibrosis service. Palliative care to consider different models of care such as short term interventions to support the patients and avoid draining resources and allowing patients to live their life when well</td>
</tr>
<tr>
<td>Hesitancy by Cystic Fibrosis Specialists introducing palliative care</td>
<td>Education and training by palliative care to Cystic Fibrosis teams in how to introduce palliative care</td>
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</table>
7.10. Strengths of the Study

One of the main strengths of this study is the overall contribution to knowledge in relation to Cystic Fibrosis and palliative care. It stands alone in terms of assessing the views of patients with Cystic Fibrosis in highlighting how they feel about being reviewed by palliative care services early in their disease trajectory. A further strength of this study is that it draws on the current practice of two different Trusts. Interspersed with information from national data in Phase 2 of the study helped piece together the perception of palliative care within Cystic Fibrosis and thus influence the proposal of an integrated model for ongoing service developments. This proposed model is unique in that it is based on the results from the data and reflects the needs of patients with Cystic Fibrosis that have been previously under researched from a palliative care perspective.

This study contributes to knowledge relating to patient views and their perceptions of palliative care and what teams could do to harness these viewpoints to move services forward. In particular the lack of information about what palliative care can provide and the importance for the patients to perceive palliative care as part of the Cystic Fibrosis team is pivotal.

The use of a mixed method study has offered valuable perspectives on the issues between Cystic Fibrosis and palliative care teams. Being able to understand what both Cystic Fibrosis and palliative care teams are currently offering to patients whilst understanding in more depth why some of these occurrences happen is insightful in strengthening integration between these
two services. Changes to services will require discussions within organisations and cultural changes to the perception of palliative care which may be a challenge for some teams depending on the existing views of palliative care and organisational influences.

7.11. Limitations of the Study
The total number of questionnaires distributed was small but represented the specialist Cystic Fibrosis adult centres at this time. Returned questionnaires, for the survey which informed phase 2 of the study, was 61%, this response could have been increased by the avoidance of forwarding the questionnaires leading up to the summer holidays. A further limitation in the study relates to the lack of doctors interviewed in Phase 3. As doctors often initiate the referral to palliative care, their views would have been helpful. Although medical staff were approached to be interviewed, they did not come forward to participate. The majority of people with Cystic Fibrosis are diagnosed in childhood and this study is limited to adults only and is therefore recognised as being limited in its transferability to all services providing Cystic Fibrosis and palliative care.

7.12. Implications for Future Research
This innovative study recruited participants from several different Cystic Fibrosis and palliative care services across the United Kingdom, however only two centres formed part of the semi structured interviews. Taking this research wider to other Cystic Fibrosis centres may result in more generalizable findings and help understand how patients and professionals feel about an
earlier referral to palliative care for patients with Cystic Fibrosis. A further consideration for future research should consider a more longitudinal approach in assessing the benefit of palliative care being involved earlier in the patient’s disease journey and the outcomes as the end of life approaches. Considering comparing patients and families’ experience of current practice against integrated care when palliative care was involved early in the patient’s illness and followed through to bereavement for the families would help in determining if palliative care affects the long term bereavement follow up for carers. The development of triggers to guide clinicians should be developed as a pilot to research if this would change the way that specialists working in Cystic Fibrosis

7.13. Summary

There are many challenges that face palliative care in being viewed as a service that can be accessed anywhere in the disease journey. If it is to be based on need then patients with Cystic Fibrosis have an established symptom burden and therefore a need is established. Funding around end of life care places tensions between services and resources and there results in competing priorities between the palliative care service. Patients with Cystic Fibrosis have identified that they want to know who is looking after them and though different ways of working with a more integrated approach to care and flexibility for patients to dip in and out of the service within which organisations require to listen to the needs of the patient. The following chapter will offer a conclusion of the study.
CHAPTER 8: CONCLUSION OF THESIS

This study has been undertaken to contribute to the existing body of knowledge between Cystic Fibrosis and palliative care. The rationale behind the choice of the research subject was two-fold. Exposure to delivering a service to patients with Cystic Fibrosis highlighted a question when it became apparent that palliative care services were only accessed at the end of a patient’s life. This study is innovative in that it is the first study to ascertain the wishes of adult patients with Cystic Fibrosis and their views on palliative care being involved earlier in their disease pathway. Following further exploration of this topic through the literature, it became apparent that the focus of palliative care and Cystic Fibrosis research was based mainly on end of life and bereavement care. The need for further research into the acceptability of palliative care earlier in the patient’s illness within this speciality was important to explore in a changing NHS climate with limited resources and a focus towards integrated care for chronic illness.

This study has been underpinned by mixed methods and a theoretical model of integrated care. The methodology allowed the researcher to see the research topic through different lenses and different perspectives from patients and professionals. Within this three phase study, data have been gathered from experts in Cystic Fibrosis and palliative care as well as patients living with Cystic Fibrosis. This study has identified not only how professionals and patients perceive palliative care but has also illustrated current practices of service provision between the two specialities from a national perspective.
The findings from this study have highlighted the need for a more integrated approach between Cystic Fibrosis and palliative care services. Patients voiced that they would like information regarding what a palliative care service can offer. They require a service where they feel they have a relationship with the palliative care team and are known to them throughout their illness. The theoretical model of integration between Cystic Fibrosis and palliative care highlights a way for professionals and commissioners to consider what an integrated service would look like. It is cognisant of how patients would like the services configured and what they feel would be best for them. Introducing the proposed integrated model from within this study would be instrumental in providing equity of access to palliative care services for patients and equip professionals in deciding which patients to refer to palliative care in a timely way before death is imminent. This research has offered insight into how integrated care could be achieved between palliative care and Cystic Fibrosis. The findings are timely as palliative care teams await the final report from the National Funding review due in January 2015. Preliminary reports from this have already suggested future funding will be based on the needs of the patients which will help palliative care in the reconfiguration of services. In considering the provision of future integrated services, incorporating the patients' needs alongside professional expertise will be pivotal in ensuring palliative care does not remain limited to end of life care for patients with Cystic Fibrosis.
REFERENCES


Association of Palliative Medicine, (APM) (2012) *Commissioning Guidance for Specialist Palliative care: Helping to Deliver Commissioning Objectives, December 2012. Guidance Document Published Collaboratively with the*


Critical Appraisal Skills Programme (CASP), (2013) Qualitative Research Checklist. United Kingdom: CASP.

Critical Appraisal Skills Programme (CASP), (2013) Quantitative Research Checklist. United Kingdom: CASP.


Health Foundation (2014) Person-Centred Care Made Simple. United Kingdom: Health Care Foundation.


Appendix 1. Reflections on part of data collection (2nd Interview)

This interview with the patient was interesting. She really did not know what Palliative care was about and when prompted felt it was about death. This was based on what she had observed on television. I don’t think I had considered that someone might have very limited knowledge of Palliative care. The patient knew what a Macmillan Nurse was but then associated Palliative care with cancer. This interview demonstrated that there might be some patients who know very little about Palliative care other than what had been observed through external sources. This interview made me realise that as in Grounded Theory aiming to recruit participants who had been referred to Palliative care would be helpful exploring if this group of patients already referred to a Palliative care service felt the same.

This patient was breathless throughout the interview and I had to remind myself not to be side tracked in trying to help her symptoms as I would do in the clinical setting but to focus on the research.
Appendix 2. Research Approval

Miss Anna-Marie Stevens
The Royal Marsden NHS Foundation Trust
Fulham Road
London
SW3 6JJ

Miss Anna-Marie Stevens

ID: CCR3872
An exploration of early palliative care in the adult Cystic Fibrosis population

Thank you for your letter dated 30 July 2012 in response to Committee for Clinical Research (CCR) outcomes letter dated 10 July 2012. The documentation and information provided was reviewed and approved by the CCR Deputy Chair on 2 August 2012.

I am pleased to inform you that the R&D Office has received all outstanding documentation with regard to the above project as follows:

- Protocol version 2 dated 06.10.2012
- The following Patient Information Sheets and Consent forms:
  - PIS Focus Group (app 2) version 2 dated 05.10.2012
  - ICF Focus Group (app 3) version 2 dated 05.10.2012
  - PIS Health Professional Survey (app 6) version 2 dated 05.10.2012
  - PIS Health Professional Interview (app 8) version 2 dated 05.10.2012
  - ICF Health Professional Interview (app 10) version 2 dated 05.10.2012
  - PIS Patient (app 11) version 2 dated 05.10.2012
  - ICF Patient (app 13) version 2 dated 05.10.2012
  - GP letter Health Professional - GP & Medical Team (app 14) version 2 dated 05.10.2012
- REC approval dated 22.11.2012 (06.12.2012 - Corrected Copy)

This confirms R&D approval for the above study to commence with effect from the date of this letter.

Please note that the patient participation in this study should be recorded on the “Maintain CCR Protocols (CCRPAX)” computer system on the HIB and the original completed consent form should be kept in the trial master file, a copy should be given to the patient and a copy should be kept in the patient’s notes.

Please be aware that the R&D Office must be notified of the following as they arise:

- Amendments
- Progress Reports
- Closure of study

Please ensure that you notify the main REC where necessary with regards to the above.

Please note, in order to publish the results of clinical trials in an ICMJE journal, your trial must be registered on either www.controlledtrials.com or www.clinicaltrials.gov before your first patient is
Appendix 2. Research Approval

recruited. For further information, please refer to http://www.dh.gov.uk/assetRoot/04/11/42/45/04114245.doc.

You are reminded that your project must be conducted in accordance with the Research Governance Framework for Health and Social Care (2nd edition 2006) and that all members of the research team must be aware of and understand their responsibilities under this Framework.

Tissue studies are to be conducted in accordance with the Human Tissue Act 2004 and the Codes of Practice issued by the Human Tissue Authority. Where tissue is used for human application please make sure that you abide by the requirements of the Human Tissue (Quality and Safety for Human Application) Regulations 2007, especially with regards to reporting of serious adverse events.

Where material is transferred outside RMH/ICR please make sure you have either appropriate transfer provisions in the study site agreement or a Material Transfer Agreement (MTA) in place prior to the commencement of this aspect of the study.

Your research is covered by NHS indemnity, but failure to report the above and comply with the regulations covering your trial may invalidate this. You should also be reminded of the need to adhere to Data Protection. In particular, please be reminded that no patient identifiable data should be stored on personal laptops or other personal storage facilities.

Please note that the most up to date guidance and forms are available on the RMH intranet site at Home/Other Departments and teams: Clinical Research & Development and on the ICR intranet site at Corporate Information/Departments/ Academic Services.

If there is any way in which R&D can assist your research please do not hesitate to contact us.

Yours sincerely

Joanne Butlers

Clinical R&D Coordinator

cc: Joanne Culver
Appendix 3. Ethical Approval

22 November 2012

Dr Joy Ross
Consultant in Palliative Medicine
The Royal Marsden NHS Foundation Trust
Fulham Road
London
SW3 6JJ

Dear Dr Ross

Study title: A mixed methods study exploring the introduction of early palliative care to adult patients with Cystic Fibrosis and to understand the perceptions of staff and patients of such a referral

REC reference: 12/LO/1392
Protocol number: CCR3872

Thank you for your letter of 05 October 2012, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS 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.
Appendix 3. Ethical Approval

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study 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 a NHS organisation’s role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the 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 final list of documents reviewed and approved by the Committee is as follows:

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Appendix 3. Ethical Approval

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Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

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
- Notification of serious breaches of the protocol
- 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.

Feedback

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.

Further information is available at National Research Ethics Service website > After Review

12/LO/1392 Please quote this number on all correspondence

With the Committee’s best wishes for the success of this project
Appendix 3. Ethical Approval

Yours sincerely

pp
Prof David Russell-Jones
Chair

Email: NRESCommittee.SECoast-Surrey@nhs.net

Enclosures: “After ethical review – guidance for researchers”

Copy to: Mrs Jane Lawrence, The Royal Marsden NHS Foundation Trust
Appendix 4.

Invitation Letter / Focus Group
Dear

I am writing to invite you to take part in a focus group as part of a study by the Royal Marsden and Royal Brompton Palliative care service and the University of Surrey.

We are conducting a study exploring the introduction of Palliative care to adult patients with Cystic Fibrosis (CF). We are keen to also determine if there is a need for referral to Palliative care in adult patients with CF and to examine staff perceptions of introducing a Palliative care service as part of the care of this group of patients at any stage of the adult patient with CF disease trajectory.

The first phase of this study is to determine questions to be asked in a survey. The survey will be forwarded to the CF centres in the United Kingdom and their respective Palliative care services. In order to develop domains and questions for this survey an expert panel of CF and Palliative care clinicians will be established to create the domains for this survey. Patient participation will also be included in the focus group.

I have attached a copy of the information sheet (attach appendix 2) for you to read.

Once you have made a decision about whether to participate I would be most grateful if you could either email me at anna-marie.stevens@rmh.nhs.uk or contact the Palliative care secretary on 0207 808 2761 to let us know your decision.

If you wish to participate, once we receive a reply from you we will contact you to arrange a convenient time and place for the focus group.

If we have not heard from you within 2 weeks from the date of this letter we will contact you by telephone to remind you about the study and arrange a time and day for the focus group if you are willing to participate.

Thank you for reading this letter and for considering taking part in this research.

Yours sincerely
Anna-Marie Stevens
Macmillan Nurse Consultant Palliative care
The Royal Marsden and Royal Brompton Palliative care Service
Department of Palliative Medicine
Royal Marsden NHS Foundation Trust
Chelsea,
London
0207 808 2761
Appendix 5.

Information sheet (Focus Group)

An exploration of early Palliative care in the adult Cystic Fibrosis population

(A mixed method study exploring the introduction of Palliative care to adult patients with Cystic Fibrosis (CF) and to understand the perceptions of staff and patients of such a referral).

Protocol number:

‘We would like to invite you to take part in a study. Before you decide, it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information and please ask us if there is anything that is not clear or if you would like more information. Thank you for reading this’

What is the purpose of the study?

This study is trying to find out what professionals understand about Palliative care. We are particularly interested in understanding at what point do staff consider making a referral to Palliative care and for what reasons. We are also keen to identify how staff perceive a referral to Palliative care.

This study is a 3 phase study. The first phase will involve developing domains and questions for a survey that will be forwarded to CF and Palliative care specialists in the United Kingdom. In order to develop the correct questions for this survey an expert panel of CF and Palliative care experts will be established to help with this.

Why have I been chosen?

You have been invited to take part because you are an expert health professional in Cystic Fibrosis or Palliative care and are working at a specialist centre caring for patients with Cystic Fibrosis.

Do I have to take part?

It is up to you whether or not you take part. If you decide to take part you will be given this information sheet to keep and you will be asked to sign a consent form.

What will happen to me if I take part?
You will be part of a focus group that will be made up of clinicians working locally within CF and Palliative care. The focus group will also be supported by patient representation. The focus group will take place at a time and place convenient to you. The focus group will be audiotaped and will be facilitated by the researcher.

**Will my taking part in this study be kept confidential?**

If you consent to take part in the research your identity will be kept strictly confidential. You will not be identified in any report or publication that arises as a result of the study. Your audiotape recording and raw data taken from the audiotapes will be anonymised and stored securely. Sections of your interviews may be transcribed and used in publications including academic medical, education journals and/or conference presentations however anonymity will always be preserved.

**What will happen to the results of the study?**

The results of the study will not be available for about 2 years. The researchers will write a report, which will be publicised at various medical meetings, and in various medical journals. If you would like a summary of the results when available please inform the researcher.

**Who is organising and funding the research?**

The study is being organised by the Royal Marsden and Royal Brompton Palliative care Service and the University of Surrey. The study is being funded by the Royal Marsden NHS Foundation Trust.

**Who has reviewed the study?**

The Royal Marsden NHS Foundation Trust/ Institute of Cancer Research’s Research and Local Ethics Committee have reviewed the study and given their approval.

**Contact for further information:**

If you would like further information about the study, then please contact the researchers (see below)
Thank you for reading this information sheet, and for considering taking part in this research.

Anna-Marie Stevens
Macmillan Nurse Consultant Palliative care
The Royal Marsden and Royal Brompton Palliative care Service
Department of Palliative Medicine
Royal Marsden NHS Foundation Trust
Chelsea,
London 0207 808 2761
Appendix 6. Consent Form/Focus Group
Appendix 6
Study Number:
Health Care Professional Identification for this trial:

CONSENT FORM

Title of Project: An exploration of early Palliative care in the adult Cystic Fibrosis Population

Name of Researcher: Anna-Marie Stevens

Please initial box

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal rights being affected.

4. I understand that everything that is said within the room will be confidential including what I say and what others in the group may say and that the focus group will be audiotaped.

5. I understand that sections of the focus group will be transcribed and used in publication including academic medical education journals and/or conference presentations and that my anonymity will be preserved.

6. I understand that I can leave the focus group at any time. I understand that at my request any sections of the audiotape that I have contributed to can be excluded from the analysis.

7. I understand that audio/ tapes will be treated as strictly confidential and will be kept in accordance with research governance policies and that any raw data on which the results of the project depend will be retained in secure storage in accordance with the Data Protection Act (1998).

8. I agree to take part in the above study.
Name of participant ___________________ Date __________ Signature __________

Name of person taking consent Date __________ Signature __________
(If different from researcher)

__________________________ ___________________
Researcher Date __________ Signature __________

When completed - 1 for the participant;
1 (original) to be kept in research site file

Would you like a summary sheet of research findings YES/NO
Appendix 7

Topic Guide for the Focus Group

After the researcher has introduced themselves, discussed the study and gained consent the focus group discussion will commence.

1. Understanding of definition of Palliative care
2. Current service provision
3. Trigger for referral to Palliative care
4. Stage of referral (influence of patient’s disease stage)
5. Barriers/Enablers to referral to Palliative care
6. Access to Palliative care
7. Are there referral criteria to support a the process of referring adult patients with CF to Palliative care
8. What would appropriate Palliative care look like
Appendix 8.

Interactions within the Focus Group

It has been acknowledged that it is important to consider the use of analytical questions to analyse important elements in the group interactions (Stevens 1996). Identifying what opinions were agreed upon and where conflict was evoked is important to consider as well as whose interests were being introduced within the group and issues relating to how the group dealt with the ideas of others need to be considered.

There was general consensus on most aspects of the issues relating to the meaning of Palliative care and the complexities around referral to Palliative care. It was clear that both teams involved within the Focus Group worked in a very different way to each other. When there was a different way of working recognised the group become supportive of the team who were not doing things in the same way to them and acknowledged that their previous experience had been similar

Reference FG 1

I sometimes think there’s a bit of a if I’m honest we don’t want to relinquish your patient over to a different team and you know we are sort of reluctant to involve a team until you know quite late on especially with patients who you’ve had a relationship with for many years and ye know if I’m honest that is partly that ye think no we’re not going to bother involve the Palliative care team ye know and we know what we’re doing sort of thing and it’s almost like you’re a bit possessive of your patient I think

Reference FG 3

I think it was a bit like that here (Brompton) to start with
Yeah

Before you guys came …

I agree I’d absolutely agree with that

It was with the CF people

Reference FG 4

Um and I guess I don’t know how much Palliative care is available in your service let alone whether they see themselves as being there for a CF group of patients

Reference FG 1

I think our Palliative care nurse would like to get involved much more to be honest cos she’s been she’s quite new to to the hospital and I don’t think she think she’s got enough to do (laugh)

Reference FG 4

And what do you think stops her getting involved

Reference FG 1

Us probably to be honest, us not referring people ye know ..what I said before being a bit possessive ye know

Reference FG 1

We tend we tend not to involve the nurse (voice goes really quiet) unless…things are really ….we are really struggling

Reference FG 5

Yeah and there is sometimes I mean we have that don’t we sometimes that a nurse can go in but you you sense that you’re not either being believed or you
know they want the assurance often from a consultant emm on AICU in particular there’s … once they know you there is … but they still often it’s consultant to consultant that actually makes the decision change especially on somewhere like AICU I think

Common experiences were discussed in terms of finding it difficult to share Patients with Cystic Fibrosis with the Palliative care team and whilst differences in the teams were perceived there were shared commonalities relating to the association of Palliative care with death and dying and the concerns around dispelling hope if Palliative care was involved. It would have been easy for the viewpoint of the team to be silenced where there was less integration between Cystic Fibrosis and Palliative care but the other group members encouraged them to talk about the differences with the support of the moderator.
Appendix 9. Questionnaire design checklist based on De Vaus (2002).

<table>
<thead>
<tr>
<th>Questionnaire design checklist</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is the research question clear</td>
</tr>
<tr>
<td>What is the content of the question designed to measure</td>
</tr>
<tr>
<td>If the question is about an attitude or belief, what is it that you want to know</td>
</tr>
<tr>
<td>Is each question (reliable, valid, likely to achieve a good response, have the same meaning to all respondents)</td>
</tr>
<tr>
<td>Is the specific wording suitable</td>
</tr>
<tr>
<td>What time of response format does the research question require (open, closed)</td>
</tr>
<tr>
<td>What level of measurement do you want the item to achieve (nominal, ordinal, interval)</td>
</tr>
<tr>
<td>For closed questions, which format rating, scores, ranking, checklist</td>
</tr>
<tr>
<td>How will non-committal responses be handled (middle response or don’t know be available)</td>
</tr>
<tr>
<td>Are clear instructions provided throughout the questionnaire</td>
</tr>
<tr>
<td>Is there sufficient space</td>
</tr>
<tr>
<td>Are any skips clear and easy to follow</td>
</tr>
<tr>
<td>Does the order of questions conform to the principles of question order</td>
</tr>
<tr>
<td>How will data be entered onto the computer</td>
</tr>
<tr>
<td>Will pilot testing be used</td>
</tr>
<tr>
<td>Do the questions work</td>
</tr>
</tbody>
</table>
## Appendix 10. Question Wording Checklist (De Vaus 2002)

<table>
<thead>
<tr>
<th>Question Wording Checklist</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is the language simple</td>
</tr>
<tr>
<td>Can the question be shortened</td>
</tr>
<tr>
<td>Is the question double-barrelled</td>
</tr>
<tr>
<td>Is the question leading</td>
</tr>
<tr>
<td>Is the question negative</td>
</tr>
<tr>
<td>Is the respondent likely to have the necessary knowledge</td>
</tr>
<tr>
<td>Is there a prestige bias</td>
</tr>
<tr>
<td>Will the words mean the same to everyone</td>
</tr>
<tr>
<td>Is the question ambiguous</td>
</tr>
<tr>
<td>Is the question too precise</td>
</tr>
<tr>
<td>Is the frame of reference for the question sufficiently clear</td>
</tr>
<tr>
<td>Does the question artificially create opinions</td>
</tr>
<tr>
<td>Is personal or impersonal wording preferable</td>
</tr>
<tr>
<td>Is the question wording unnecessary detailed or objectionable</td>
</tr>
<tr>
<td>Does the question have dangling alternatives</td>
</tr>
<tr>
<td>Does the question contain gratuitous qualifiers</td>
</tr>
<tr>
<td>Is the question a dead giveaway</td>
</tr>
</tbody>
</table>
Appendix 11

Sample of Questionnaire

A survey to explore Cystic Fibrosis and Palliative Care

Referral Patterns

1. In your hospital, are patients with Cystic Fibrosis routinely referred to Palliative Care?
   ○ Yes
   ○ No

2. Why do you think patients with Cystic Fibrosis may not be routinely referred for Palliative Care? Please tick all that apply
   ○ Cystic Fibrosis team is able to support Palliative Care needs
   ○ Insufficient staff training
   ○ Lack of palliative care resources to see Cystic Fibrosis patients other than at end of life
   ○ Patients with Cystic Fibrosis do not want to be referred to Palliative Care
   ○ Difficulty in determining when to refer to Palliative Care

Please expand
3. In your hospital how are the referrals made between Cystic Fibrosis and Palliative Care? Please tick all that apply

☐ Through joint Multidisciplinary Team Meetings
☐ Through the use of a referral form
☐ Through a telephone referral
☐ No formal referral pattern

Other (please specify)

4. Are you a professional whose speciality is Cystic Fibrosis?

☐ Yes
☐ No

Other (please specify)

5. How many patients with Cystic Fibrosis are seen within your unit annually?

☐ over 103
☐ 50-99
☐ 25-49
☐ 10-24
☐ 1-9
☐ 0

Other (please specify)

6. How many patients with Cystic Fibrosis have you referred for transplant in the last 12 months.

Please answer in the box below.


7. Are patients with Cystic Fibrosis referred for palliative care when they are placed on the transplant list

☐ Yes
☐ No
8. Approximately how many patients were referred in the last 12 months between Cystic Fibrosis and Palliative Care Teams within your hospital

- Over 100
- 50-99
- 25-49
- 10-24
- 1-3
- 0

Other (please specify)

9. How often do the Cystic Fibrosis and Palliative Care Teams meet to discuss patients

- Weekly
- Monthly
- Never

Other (please specify)
10. To what extent is there integration between the Cystic Fibrosis and Palliative Care Teams within your hospital

- Full integration (Cystic Fibrosis and Palliative Care teams working closely together, meeting regularly, using shared guidelines for the management of symptoms)
- Partially integrated
- Not integrated

Other (please specify)

11. Please indicate below which definition of Palliative Care best fits your current practice

- Palliative Care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families

- Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual. It is applicable early in the course of the illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

Other (please specify)
12. Please tick below all the statements that reflect the referral reason between Cystic Fibrosis and Palliative Care Services.

- Symptom Control
- Psychological Support
- End of Life Care
- Advance Care Planning
- Community Support
- Support with family discussions
- Support with end of life care pathways
- Bereavement Support
- Patients with Cystic Fibrosis are not referred to Palliative Care

Other (please specify)

13. Of the statements you selected in Question 12 please rate your top 3 responses from 1-3 where 1 is the most common reason for referral and 3 is the least. (responses from 4-9 will not be analysed)

- Symptom Control
- Psychological Support
- End of Life Care
- Advance Care Planning
- Community Support
- Support with family discussions
- Support with end of life care pathways
- Bereavement Support
- Patients are not referred for Palliative Care
Models of Care

14. In your opinion when is the best time to introduce palliative care to patients with Cystic Fibrosis?

☐ Early in the disease pathway before unresolved symptoms are present
☐ When symptoms are becoming difficult to manage
☐ For support in the community
☐ When assessment for transplantation is being considered
☐ When the patient is reaching the end of life phase

Other (please specify)

15. Of the statements you ticked above please rate your responses form 1-3, where 1 is the most important and 3 the least. (Responses 4-5 will not be analysed)

☐ Early in the disease pathway before unresolved symptoms are present
☐ When symptoms are becoming difficult to manage
☐ For support in the community
☐ When assessment for transplantation is being considered
☐ When the patient is reaching the end of life
16. Which model of service exists between Cystic Fibrosis and Palliative Care Teams in your hospital?

- Consultative only for patients with complex needs
- Concurrent management throughout the course of Cystic Fibrosis (both Cystic Fibrosis and Palliative Care follow the patient up)
- Concurrent management once treatment options are becoming limited

Other (please specify)

---

17. In your hospital are there guidelines to support when patient referrals between Cystic Fibrosis and Palliative Care should happen?

- Yes
- No

Other (please specify)
18. If you were setting up your service again would you change anything about the way the Cystic Fibrosis and Palliative Care teams work together. If the answer to this question is yes please expand in the free text box below

☐ Yes
☐ No

Other (please specify):

19. Within your team please list below the numbers per head of professionals within each group that make up your core team and their respective whole time equivalent (WTE)

<table>
<thead>
<tr>
<th>Professional Role</th>
<th>WTE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Consultant</td>
<td></td>
</tr>
<tr>
<td>Nurse Consultant</td>
<td></td>
</tr>
<tr>
<td>Lead Nurse</td>
<td></td>
</tr>
<tr>
<td>Clinical Nurse Specialist</td>
<td></td>
</tr>
<tr>
<td>Allied Health Care Professional</td>
<td></td>
</tr>
<tr>
<td>Specialist Registrar in Training</td>
<td></td>
</tr>
<tr>
<td>Psychologist</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>
20. Please indicate below the length of time you have been working in your area of speciality

- <1 year
- 1-2 years
- 3-10 years
- over 10 years
- Other (please specify)

21. Please write any additional comments you would like to add regarding service provision between the Cystic Fibrosis and Palliative Care Teams within your hospital
Appendix 12

Invitation Letter to Professionals/Survey

Dear

I am writing to invite you to take part in a survey as part of a study conducted by the Royal Marsden and Royal Brompton Palliative care service and the University of Surrey. We are conducting a study exploring the introduction of Palliative care to adult patients with Cystic Fibrosis (CF). We are keen to also determine if there is a need for referral to Palliative care in adult patients with CF and to examine how both CF and Palliative care teams currently work together. We are also interested in identifying any triggers for referrals to Palliative care or potential barriers.

This survey involves part of a larger study that includes interviewing patients and staff in two specialist CF centres.
I have attached a copy of the information sheet (Appendix 6) for you to read.

Once you have made a decision about whether to participate I would be most grateful if you could complete the online survey

If we have not heard from you within 2 weeks from the date of this letter we will send an email to remind you about the study.

Thank you for your time in considering participating in this study

Yours sincerely

Anna-Marie Stevens
Macmillan Nurse Consultant Palliative care
The Royal Marsden and Royal Brompton Palliative care Service
Department of Palliative Medicine
Royal Marsden NHS Foundation Trust
Chelsea,
London
0207 808 2761
Appendix 13

Health professional information sheet (Survey)

An exploration of early Palliative care in the adult Cystic Fibrosis population

(A mixed method study exploring the introduction of Palliative care to adult patients with Cystic Fibrosis (CF) and to understand the perceptions of staff and patients of such a referral).

Protocol number:

‘We would like to invite you to take part in a study. Before you decide, it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information and please ask us if there is anything that is not clear or if you would like more information. Thank you for reading this’

What is the purpose of the study?

This study is trying to find out what professionals understand about Palliative care. We are particularly interested understanding at what point do staff consider making a referral to Palliative care and for what reasons. We are also keen to identify current working patterns between Cystic Fibrosis and Palliative care teams. This survey is part of a larger study that will also look at the views and feelings of patients and the staff involved in their care. The aim of the study is to explore the introduction of Palliative care to adult patients with CF and to understand the perceptions of staff and patients of such a referral.

Why have I been chosen?

You have been invited to take part because you are a health professional working at a specialist centre caring for patients with CF.

Do I have to take part?

It is up to you whether or not you take part. If you decide to take part you will be given this information sheet to keep. In returning the completed survey this will be viewed that consent has been given to participate in this research.

What will happen to me if I take part?

You will be asked to complete an online survey by the researcher. This will take about 20-30 minutes to complete.
Will my taking part in this study be kept confidential?

If you consent to take part in the research your identity will be kept strictly confidential. You will not be identified in any report or publication that arises as a result of the study. Your reply to the survey questions will be returned to a secure email address which will be anonymised and stored securely.

What will happen to the results of the study?

The results of the study will not be available for about 2 years. The researchers will write a report, which will be publicised at various medical meetings, and in various medical journals. If you would like a summary of the results when available please inform the researcher.

Who is organising and funding the research?

The study is being organised by the Royal Marsden and Royal Brompton Palliative care Service and the University of Surrey. The study is being funded by the Royal Marsden NHS Foundation Trust.

Who has reviewed the study?

The Royal Marsden NHS Foundation Trust/ Institute of Cancer Research’s Research and Local Ethics Committees have reviewed the study and given their approval.

Contact for further information:

If you would like further information about the study, then please contact the researcher (see below)
Thank you for reading this information sheet, and for considering taking part in this research.

Anna-Marie Stevens
Macmillan Nurse Consultant Palliative care
The Royal Marsden and Royal Brompton Palliative care Service
Department of Palliative Medicine
Royal Marsden NHS Foundation Trust
Chelsea,
London
0207 808 2761
Appendix 14.

**Topic Guide for Professionals**

*After the researcher has introduced themselves, discussed the study and gained consent the interview will commence.*

1. What is your understanding of the term Palliative care
2. Have you referred anyone to Palliative care
3. What is the perception of such a referral
4. Where was the patient in terms of stage of disease/ Timing of referral
5. What Triggers made you think of referring to Palliative care
6. What if anything has prevented you from referring to Palliative care
7. What would appropriate access to Palliative care look like?
Appendix 15

Topic Guide for Patients

After the researcher has introduced themselves, discussed the study and gained consent the interview will commence.

1. Have you heard of the term Palliative care
2. What is your understanding of the term Palliative care
3. Have you been seen by anyone from a Palliative care team
4. Does being referred to Palliative care mean anything to you
5. When do you think would be a good time to meet the Palliative care team
6. Would you like the name Palliative care to be something different? i.e. symptom control
Appendix 16

Patient Information Sheet (Interview)

An exploration of early Palliative care in the adult Cystic Fibrosis population

(A mixed method study exploring the introduction of Palliative care to adult patients with Cystic Fibrosis (CF) and to understand the perceptions of staff and patients of such a referral).

Protocol number:

‘We would like to invite you to take part in our study. Before you decide, it is important for you to understand why the research is being done and what it will involve for you. One of our team will go through the information sheet with you and answer any questions you have.

Please take time to read the following information carefully and discuss it with friends, relatives and your doctor if you wish. Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.
Thank you for reading this’

What is the purpose of the study?

This study is trying to find out about what you and the staff caring for you understand by the term Palliative care. We would like to try and find out when would be a good time for your doctors and nurses to ask for help for you from the Palliative care team.

We are studying patients like you who are cared for by the specialist Cystic Fibrosis centre at your hospital and who may need additional treatment and support from time to time.

This study will look at your views and feelings, as well as those of the hospital doctors, nurses, dieticians and physiotherapists. The aim of the study is to better understand how you and the professionals caring for you feel about Palliative care services and the best time for you to be seen by the Palliative care team..

Why have I been invited to take part?

You have been invited to take part because you are a person with Cystic Fibrosis attending the specialist centre. We are inviting other people in a similar situation to you to take part in the study.
**Do I have to take part?**

It is up to you to decide to join the study. We will describe the study and go through this information sheet. If you decide to take part you will be given this information sheet to keep and you will be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

**What will happen to me if I take part?**

You will be visited either at home, in the hospital (or elsewhere if more convenient to you) by the researcher and take part in an interview with the researcher. You will be asked some basic questions about yourself and then you will be interviewed specifically regarding your feelings and views about Palliative care and any information you can share with researcher about when you feel would be a good time for Palliative care services to be introduced into your treatment. This interview will be audiotaped and is likely to last between 45 minutes to one hour.

**What are the possible disadvantages of taking part?**

Taking part in the study will not adversely affect any aspect of your treatment at home or in hospital. Sometimes being asked about your feelings may be difficult to answer. If so, you do not have to continue or answer anything you do not feel comfortable with. You can stop the interview at any time and if you do not wish to continue the audio recording the recording will be erased and the information provided will not be included in the study. If you feel after answering our questions you need more support to deal with any emotions you have we will arrange this for you.

**What are the possible benefits of taking part?**

We cannot promise the study will help you but the information we get from this study will help improve the way we deliver Palliative care services to people with Cystic Fibrosis. These interviews are part of a larger study looking at what patients and staff understand about Palliative care and when is the best time for Palliative care services to be involved in your care.

**What if there is a problem?**

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The names of the researcher and the supervisors of this study are listed below
If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. You can contact the Patient Advice and Liaison Services office your hospital.

**Will my taking part in this study be kept confidential?**

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. If you consent to take part in the research, any of your medical records may be looked at by a member of the research team or regulatory authority. Your name, however, will not be disclosed. You will not be identified in any report or publication that arises as a result of the study. Your audiotape recording will be anonymised and stored securely. Sections of your interviews may be transcribed and used in publications including academic medical education journals and/or conference presentations however anonymity will always be preserved.

**What will happen if I don’t want to carry on with the study?**

You will be free to withdraw from the study at any time. This will not prejudice the care you receive in any way. If you withdraw from the study we will destroy any information you have shared with us.

**Will my General Practitioner / Family doctor (GP) be informed of my involvement?**

Provided you consent to this, your GP will be informed that you are participating in the study.
What will happen to the results of the study?

The results of the study will not be available for about 2 years. The researchers will write a report, which will be publicised at various medical meetings, and in various medical journals. If you would like a summary of the results when available please inform your doctor or research nurse.

Harm

If the event that something does go wrong and you are harmed during the research and this is due to someone’s negligence then you may have grounds for legal action for compensation against your hospital but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you. NHS indemnity does not offer no-fault compensation i.e. for non-negligent harm, and NHS bodies are unable to agree in advance to pay compensation for non-negligent harm.

Who is organising and funding the research?

The study is being organised by the Royal Marsden and Royal Brompton Palliative care Service and the University of Surrey. The study is being funded by the Royal Marsden NHS Foundation Trust. The researchers will not be paid for including you in the study.

Who has reviewed the study?

All research in the NHS is looked at by an Independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by South East Coast-Surrey Ethics Committee in addition approval has been gained from local research and development offices at your hospital.

Contact for further information:

If you would like further information about the study, then please contact the researcher (see below)
Thank you for reading this information sheet, and for considering taking part in this research.

Anna-Marie Stevens
Macmillan Nurse Consultant Palliative care
The Royal Marsden and Royal Brompton Palliative care Service
Department of Palliative Medicine
Royal Marsden NHS Foundation Trust
Chelsea,
London
0207 808 2761
Appendix 17

Health professional information sheet (Interviews)

An exploration of early Palliative care in the adult Cystic Fibrosis population

(A mixed method study exploring the introduction of Palliative care to adult patients with Cystic Fibrosis (CF) and to understand the perceptions of staff and patients of such a referral).

Protocol number:

'We would like to invite you to take part in a study. Before you decide, it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information and please ask us if there is anything that is not clear or if you would like more information. Thank you for reading this'

What is the purpose of the study?

This study is trying to find out what professionals understand about Palliative care. We are particularly interested understanding at what point do staff consider making a referral to Palliative care and for what reasons. We are also keen to identify how staff perceive a referral to Palliative care.

This study will look at the views and feelings of patients and the staff involved in their care. The aim of the study is to explore the introduction of Palliative care earlier to adult patients with CF and to understand the perceptions of staff and patients of such a referral.

Why have I been chosen?

You have been invited to take part because you are a health professional working at a specialist centre caring for patients with CF. You have also been chosen as you have more than 1 year of experience working with patients with CF. We are also interviewing patients regarding their opinions.

Do I have to take part?

It is up to you whether or not you take part. If you decide to take part you will be given this information sheet to keep and you will be asked to sign a consent form.

What will happen to me if I take part?

You will be interviewed by the researcher at a time and place convenient to you. The interview will be audiotaped. The interview will be semi-structured
and contain questions specifically regarding your feelings and views about palliative. The interview is likely to last between 45 minutes to one hour.

**Will my taking part in this study be kept confidential?**

If you consent to take part in the research your identity will be kept strictly confidential. You will not be identified in any report or publication that arises as a result of the study. Your audiotape recording and raw data taken from the audiotapes will be anonymised and stored securely. Sections of your interviews may be transcribed and used in publications including academic medical education journals and/or conference presentations however anonymity will always be preserved.

**What will happen to the results of the study?**

The results of the study will not be available for about 2 years. The researchers will write a report, which will be publicised at various medical meetings, and in various medical journals. If you would like a summary of the results when available please inform the researcher.

**Who is organising and funding the research?**

The study is being organised by the Royal Marsden and Royal Brompton Palliative care Service and the University of Surrey. The study is being funded by the Royal Marsden NHS Foundation Trust

**Who has reviewed the study?**

The Royal Marsden NHS Foundation Trust/ Institute of Cancer Research’s Research and Local Ethics Committees have reviewed the study and given their approval.

**Contact for further information:**

If you would like further information about the study, then please contact the researcher (see below)
Thank you for reading this information sheet, and for considering taking part in this research.

Anna-Marie Stevens
Macmillan Nurse Consultant Palliative care
The Royal Marsden and Royal Brompton Palliative care Service
Department of Palliative Medicine
Royal Marsden NHS Foundation Trust
Chelsea,
London
0207 808 2761
Appendix 18. Patient Consent Form

Centre Number:
Study Number:
Patient Identification for this trial:

CONSENT FORM

Title of Project: An exploration of early Palliative care in the adult Cystic Fibrosis Population

Name of Researcher: Anna-Marie Stevens

Please initial box

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3. I understand that sections of any of my medical notes may be looked at by responsible individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.

4. I understand that my participation will be audio taped

5. I understand that sections of my interviews will be transcribed and used in publication including academic medical education journals and/or conference presentations and that my anonymity will be preserved.

6. I understand that I can stop the interview at any time if I do not wish to continue the audio recording and that the recording will be erased and the information provided will not be included in the study.

7. I understand that audio/video tapes will be treated as strictly confidential and will be kept in accordance with research
governance policies and that any raw data on which the results of the project depend will be retained in secure storage in accordance with the Data Protection Act (1998).

8. I agree to my GP and medical team being notified of my agreement to take part in this study.

9. I agree to take part in the above study.

______________________________  _________________________  ______________
Name of patient                  Date                                     Signature

______________________________  _________________________  ______________
Name of person taking consent    Date                                     Signature
(if different from researcher)

______________________________  _________________________  ______________
Researcher                      Date                                     Signature

When completed - 1 for patient;
1 (original) to be kept in research site file;
1 for medical notes;

Would you like a summary sheet of research findings  YES/NO
Appendix 19. Health Care Professional Consent Form/Interviews

Study Number: 
Health Care Professional Identification for this trial: 

CONSENT FORM

Title of Project: An exploration of early Palliative care in the adult Cystic Fibrosis Population

Name of Researcher: Anna-Marie Stevens

Please initial box

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal rights being affected.

4. I understand that my participation will be audio taped

5. I understand that sections of my interviews will be transcribed and used in publication including academic medical education journals and/or conference presentations and that my anonymity will be preserved.

6. I understand that I can stop the interview at any time if I do not wish to continue the audio recording and that the recording will be erased and the information provided will not be included in the study.

7. I understand that audio/video tapes will be treated as strictly confidential and will be kept in accordance with research governance policies and that any raw data on which the results of the project depend will be retained in secure storage in accordance with the Data Protection Act (1998)

8. I agree to take part in the above study
<table>
<thead>
<tr>
<th>Name of participant</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name of person taking consent (if different from researcher)</td>
<td>Date</td>
<td>Signature</td>
</tr>
<tr>
<td>Researcher</td>
<td>Date</td>
<td>Signature</td>
</tr>
</tbody>
</table>

**When completed -** 1 for the Health Care Professional participant;
1 (original) to be kept in research site file

Would you like a summary sheet of research findings      YES/NO
Appendix 20

Example of Field Notes (Interviews)

Interview Professional 06

Interesting interview with a specialist in the field of Cystic Fibrosis. Loaded comments regarding the relationship between the two teams. Inferred that really there isn’t much of a relationship. Was looking into space for most of the interview. Repeatedly mentioned that not referring to Palliative care was not based anything personal. Reiterated the difference with CF patients and the difficulty with their prognosis almost in an insular way that there was no way this group of patients could have similar needs to others with life limiting illnesses. This interview has questioned my own views about perceptions of Palliative care and perhaps some assumptions. I believe this participant was saying that they could manage with patients that were dying and that Palliative care was only needed as a last resort. I think my interpretation was that perceptions of Palliative care in some instances still thought of death and dying but I thought professionals had moved on. It feels like Palliative care has regressed 20 years.
## Appendix 21. Example of line by line coding

<table>
<thead>
<tr>
<th>An example of open coding Patient Transcript 06</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Yes, I do, yes. What did you study?</strong></td>
<td></td>
</tr>
<tr>
<td>Ethics.</td>
<td></td>
</tr>
<tr>
<td><strong>Oh my goodness. Gosh I’m glad... we have don’t it all properly, did you enjoy your course?</strong></td>
<td></td>
</tr>
<tr>
<td>Yes I did, yes it was good, and because I live near Watford, so it was about a forty-five minute drive to get home. So I was independent but, you know, I was kind of able to get home if I needed to. Yes so it was a really good experience.</td>
<td></td>
</tr>
<tr>
<td><strong>Did your CF interfere much with...</strong></td>
<td></td>
</tr>
<tr>
<td>It didn’t, but around my exam time, I had to redo my exams because I was unwell for those. But generally it didn’t, I mean I had such few, so few lectures that it kind of that wasn’t a problem. But yes no generally I was well throughout university. A few blips but I did some home IVs and I was able to manage it quite well.</td>
<td></td>
</tr>
<tr>
<td><strong>Yes, brilliant, that’s great isn’t it? So we have discussed this but you know what this study is about, and you’ve read the patient information leaflet. But had you heard the term ‘Palliative care’ before?</strong></td>
<td></td>
</tr>
<tr>
<td>I’d heard of it, but I didn’t really know what it meant. I mean I certainly had not heard it mentioned at the XXX. The only time it was mentioned was when I was very, was feeling very sick and that was probably about two years ago, on the Tigecycline, so they sort of brought in a couple of people to talk to me about possible sort of sickness medications. But that was, that was the only time that it’s ever really been mentioned. So I don’t really know too much about the service.</td>
<td></td>
</tr>
<tr>
<td><strong>No, and when they brought the people in, do you remember very much about what they explained to you about what they did? Or who was it that initiated it, do you remember? Not personally, but was it a nurse?</strong></td>
<td></td>
</tr>
<tr>
<td>Yes, my consultant, I think he contacted Palliative care, but it was very much a kind of, because I’d been struggling with sickness for a few days, it was kind of, ‘Oh what are the other options here?’ And then it was the Palliative care team was kind of brought in, whereas I think perhaps if it had been done earlier, it would have been better to get control sooner rather than sort of last chance. You know, ‘What else? What else is out there?’ But I think it was the consultant that kind of made the contact with the team.</td>
<td></td>
</tr>
<tr>
<td><strong>And when the team came, do you remember what they explained to you about they were going to do or?</strong></td>
<td></td>
</tr>
<tr>
<td>Yes, I mean they were very clear with, with the role of kind of – well in terms of dealing with the sickness, they didn’t say too much about their roles generally. But they said about, you know, symptom control and so that was very much what I was aware that they were there to sort of deal with. And yes they were helpful kind of with suggestions and talking things through. But it was only when I got given the leaflet that I saw about the emotional and practical sort of side, because that’s never been sort of</td>
<td></td>
</tr>
</tbody>
</table>

- Independent
- Could get home if needing to
- Positive experience studying
- Had to redo exams
- Well throughout university
- A few blips, home IV’s
- Managing to live well
- Not sure about what pall care means
- Hadn’t heard of it mentioned at XXX
- Mentioning just when sick knowing little about the service
- Was mentioned to talk about ant emetics
- Struggling with sickness
- Consultant contacted pall care as pt
Yes, sure. And how did that make you feel? Is that the information leaflet?

Yes.

That I gave you?

Yes, about the Palliative care team, yes.

Yes, did that make you have any more questions or make you think in a different way?

I suppose it just made me think, to kind of wonder what the emotional support could be offered was and just sort of – I mean mostly I feel quite, I'm quite positive and I'm very lucky in that my family are very supportive. But I think probably for patients who don’t, especially young CF patients, who don't have a supportive family, that side of it could be sort of tapped into a bit more, I think. And perhaps on admission be given a leaflet and said, you know, 'If you've got any emotional kind of issues or you want to talk things through,' because that's or you want to talk things through,' because that's never been addressed. And I think, you know, some people must struggle managing it all themselves. So that, I think, could be improved.
## Appendix 22. Risk Assessment

<table>
<thead>
<tr>
<th>Activity</th>
<th>Hazard</th>
<th>Level of Risk</th>
<th>Control/Actions</th>
<th>Who</th>
<th>When</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visiting patients in their own homes</td>
<td>Lone worker</td>
<td>Moderate</td>
<td>For personal assistant to be aware of where I am going. To notify her by phone on entering and leaving the address To follow the RM lone worker policy</td>
<td>researcher</td>
<td>before and after interviews</td>
</tr>
<tr>
<td>Being interrupted when undertaking interviews</td>
<td>interruption disrupts interviews those interviewed feel vulnerable</td>
<td>Minor</td>
<td>to ensure private area secured for interviews in the hospital prior to and on the day off the interview notices on doors stipulating not to be disturbed</td>
<td>researcher</td>
<td>prior to hospital interviews</td>
</tr>
<tr>
<td>Travelling to second site for interviews</td>
<td>travelling a distance and staff not available</td>
<td>Moderate (time and financial)</td>
<td>to telephone staff the day before and have a plan in place to be contacted in the morning of interview prior to departure is staff unable to be at the interview to try and undertake several interviews on one day</td>
<td>researcher</td>
<td>prior to interviews</td>
</tr>
<tr>
<td>Using equipment to undertake interviews (tape recorder)</td>
<td>breakdown of equipment</td>
<td>Moderate (time wastage for patient and professional)</td>
<td>have spare batteries at all times and when possible a spare recorder</td>
<td>researcher</td>
<td>ongoing through qualitative phase of the study</td>
</tr>
<tr>
<td>Patients become distressed due to the sensitivity of the subject</td>
<td>patient distress</td>
<td>Moderate</td>
<td>to offer to stop the interview and access support from the CF team or Palliative care team</td>
<td>researcher CF team and Palliative care team</td>
<td>ongoing through the qualitative phase of the study</td>
</tr>
</tbody>
</table>
Example of Theme Development (Interview) Theme 1

- Access to services
- Time points of referral to palliative care
- Access to information
- The term palliative care
- Perceptions and knowledge from patients and staff
- Concurrent active CP treatment and palliative care
- Understanding of palliative care

Open Coding

Focused Coding

Theory Development

Constant Comparative Analysis
Tables

1. Numbers of patients with CF reported by country
2. Summary of CF UK Registry 2013
3. Transplant Activity in the UK
4. Timeline of Palliative care Development
5. Research Aim and Questions
6. Advantages and limitations Qualitative and Quantitative Research
7. Reasons for selecting Mixed Method Design
8. Research Methods
9. Mixed Method Data Analysis
10. Strategies for Minimising Threat to Validity
11. Research Aim and Questions
12. Inclusion/Exclusion Criteria
13. Characteristics of a Good Moderator
14. Guide for developing Focused Codes
15. Ethical Considerations for all 3 phases of the study
16. Description of Focus Group Participants
17. Theme generated from Focus Group
18. Number of Respondents to Survey Questions
19. Reasons why patients are not routinely referred to Palliative care
20. Information generated from additional comments from Questionnaire
21. Themes generated from interviews
22. Patient participant demographics
23. Professional participant demographics
24. Theme 1 categories and sub categories
25. Theme 2 category and sub categories
26. Theme 3 category and sub categories
27. Commonalities and differences from all datasets
28. Summary of Implications for Practice
Figures
1. Models of Palliative Care
2. Databases searched for Literature Review
3. PRISMA figure of selected articles
4. Development cycle of research methodology
5. Diagrammatic representation of Research
6. Referral reason between Cystic Fibrosis and Palliative care
7. When is the best time to introduce Patients with Cystic Fibrosis to Palliative care
8. How methods helped answer the research questions
9. Example of how issues were connected through study
10. Concepts to be considered to develop an Integrated Model of Care
11. Proposed Model of Integrated Care