Clinical Academic Paper

Overview of the integration of knowledge, research and practice

Research Log

by

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AN EXPLORATION OF EARLY PALLIATIVE CARE IN ADULT PATIENTS WITH CYSTIC FIBROSIS

(SUBMITTED TO THE JOURNAL OF CYSTIC FIBROSIS NOVEMBER 2014)

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Running Title: EARLY PALLIATIVE CARE AND CYSTIC FIBROSIS

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Abstract

Background:

Cystic Fibrosis (CF) is one of the UK’s most common life limiting genetic disorders. Improvement in treatment modalities 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.

Method: Mixed Methods

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.

Conclusions:

There is 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. Currently there is limited integration between CF and PC teams with a lack of shared guidelines to work towards.
Introduction

Palliative Care should be available to all patients and their families irrespective of the stage of their disease or diagnosis (Ahmed et al. 2004; O'Leary & Tiernan 2008; Standing Medical Advisory Committee 1992). How far have we come to achieve this goal for patients with Cystic Fibrosis? Over the last 20 years Cystic Fibrosis (CF) has been transformed from a fatal diagnosis in infancy to a chronic disease of children and young adults (median age at death 26yrs). Improvement in treatment modalities has resulted in this group of patients living longer. However, there is a recognised need for Palliative Care intervention to aid symptomatic management (Stenekes et al. 2009) and to be able to support patients at different stages of their illness. 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.

A recent review of Cystic Fibrosis suggested that an integrated model between the primary treating team and specialist Palliative Care team should be the way forward (Bourke et al. 2009). This proposed model of care is echoed across other disease groups (Abernathy & Quill 2013). For this to be achieved it has been suggested that education of primary teams should be the starting point, enabling them to deliver Palliative Care whilst endorsing specialist Palliative Care consultations for complex family situations and refractory symptom control (Quill & Abernethy 2013). However to date there is little data from Cystic Fibrosis to support or refute this theory.
The ethos of Palliative Care has been deeply rooted in, and grown from within, the speciality of cancer (Clarke 2007). The WHO definition of Palliative Care reminds us that Palliative Care is applicable early within any disease journey and that it should be offered alongside life prolonging treatments such as chemotherapy and radiotherapy (WHO 2002). Population based studies show that many patients with a non-malignant disease have more burdensome symptom problems in the last year of life than patients with a cancer diagnosis (Griffin & Conway 2008). The current model of Palliative Care for cancer patients will need to evolve and adapt to meet the needs of patients with non-malignant disease (Boland et al. 2013) and further evidence is needed to better understand the needs of this patient group and to shape future service provision.

Studies looking at end of life care and advance care planning for adults with CF have been conducted (Chapman et al 2005; Iles & Lowton 2008; Mitchell 2000; Sawicki et al. 2008). It is known that this group of patients may benefit symptomatically from either direct support from a Palliative Care team or indirect through support and advice to CF professionals (Bourke et al.2009; Braithwaite et al. 2011). Pain, breathlessness and cough have all been recognised as significant problems for patients with CF (Stenekes et al. 2009).

The overall aim of this research study was to explore the acceptability of referral of patients with Cystic Fibrosis to Palliative Care earlier in their disease
trajectory. This paper describes the first 2 phases of this work and reports the results of a focus group and National Survey (UK) of Cystic Fibrosis and specialist Palliative Care services to explore current service provision and barriers to integrated working.

**Methods**

This mixed methods methodology study was approved by the local research committees of two research sites with ethical approval from South East Surrey Coast and the University of Surrey ethics committees.

Phase 1 of the study was a focus group. Specialist Palliative Care and Cystic Fibrosis experts, from different professional groups, from both participating Trusts were invited to take part (purposive sample). The focus group was facilitated by an experienced researcher, with aid of a note-taker, and was guided by a topic guide developed from a literature review. All information was recorded, transcribed verbatim and stored on N-Vivo 10 for analysis. Data analysis followed a grounded theory methodology with the development of categories and themes following constant comparative analysis.

Phase 2 of the study was a National Survey. This examined in more detail the issues that had been raised by the Focus Group in Phase 1 of the study.

A combination of open and closed question formats were used for the twenty one questions to be answered. The questionnaire was categorised into three domains. Section 1 related to referral patterns (13 questions), section 2 models of care (5 questions) and section 3 demographics of respondents (3 questions).
The survey was piloted by two independent clinical teams and adapted before distribution.

All the 23 adult specialist Cystic Fibrosis centres within the United Kingdom, listed by The Cystic Fibrosis Trust (2012), and their respective local Specialist Palliative Care services were identified either through the hospice directory or by telephoning the hospital directly. All teams were contacted by telephone to establish the clinical lead, confirm contact information and to advise them of the study. Participants were contacted two weeks in advance of the survey by letter. An email was sent with an URL link embedded that would take the participant directly to the questionnaire. Email reminders were forwarded to participants at 3 and 6 weeks post initial circulation. Data from the survey was inputted into SPSS V21 for analysis.

Results

Eight participants attended the focus group (Table 1). The overarching theme identified from the Focus Group relates to “Digging a hole” which signifies how professionals feel when discussing the issue of Palliative Care with patients. This theme was generated from categories and sub categories relating to the professional’s perceptions and meaning of Palliative Care as well as barriers and facilitators to initiating a referral between Cystic Fibrosis and Palliative Care.
Table 1: Participants attending focus group

<table>
<thead>
<tr>
<th>Profession</th>
<th>Speciality</th>
<th>Experience in speciality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical Nurse Specialist</td>
<td>CF</td>
<td>5 years</td>
</tr>
<tr>
<td>Matron Palliative Care</td>
<td>PC</td>
<td>Over 10 years</td>
</tr>
<tr>
<td>Consultant Palliative Medicine</td>
<td>PC</td>
<td>Over 10 years</td>
</tr>
<tr>
<td>Clinical Nurse Specialist</td>
<td>CF</td>
<td>Over 10 years</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>CF</td>
<td>5 years</td>
</tr>
<tr>
<td>Ward sister</td>
<td>CF</td>
<td>Over 10 years</td>
</tr>
<tr>
<td>Senior staff nurse</td>
<td>CF</td>
<td>Over 10 years</td>
</tr>
<tr>
<td>Nurse Consultant</td>
<td>CF</td>
<td>Over 10 years</td>
</tr>
</tbody>
</table>

The overall response rate to the survey was 61% (28/46); PC response rate 59% (n=16/23), CF response rate 41% (n=11/23). Of the 28 responses, eighteen questionnaires were completed fully. Of the ten 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 PC specialists, 2 CF specialists and one was unknown as only the first question was completed.

All professionals responded when asked if patients with CF were routinely referred to the PC team. Less than 50% of the teams routinely refer between CF and PC. In aiming to understand why patients with CF may not be referred and to further understand the perception of a referral to PC 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) and these can be viewed in Table 2. The most common reasons were that professionals
are unsure when to refer CF patients to PC (n=9), this was followed by over half of the respondents stating that CF teams themselves can manage Palliative Care needs.

Interestingly although Palliative Care resource was mentioned in the FG by the experts this was only stated twice and was one of the lowest reasons as to why patients may not be referred. The issue of patients themselves not wanting to be referred to PC was stated by 4 respondents, this view was explored further in Phase 3 of this study using in depth interviews.

Table 2 Reason why patients are not routinely referred to PC services (n=24 reasons from n=14 respondents)

<table>
<thead>
<tr>
<th>Reason</th>
<th>Number of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>PC</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 CF patients are referred to Palliative Care in a 12 month period. Four teams referred 10-25 patients and three teams referred 25-49 patients. One
team recognised that on occasions a patient can be referred several times
during the course of one admission.

Interestingly of the teams who answered positively to CF patients being
routinely referred to Palliative Care, 54% of these referrals were made through
the MDT meeting. Alternatively referrals are commonly made by telephone
referral. In addition one team stated they would make referrals directly to the
consultant via email.

This data needs to be interpreted in the context that 11 of the teams reported
the numbers of CF patients seen annually by their service. For those who saw
>100 patients per year, one referred 25-49 patients to PC per year, 3 referred
10-25, 4 referred 1-9 and one referred no patients to PC. The two smaller
centres who reported seeing 50-100 patients per year both referred 1-9
patients.

For the 9 CF teams that reported seeing >100 patients per year, they each
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 CF and Palliative Care and a
‘fully integrated’ service. For the six 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 PC 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 PC, neither had regular meetings with the PC services.

Full integration (Cystic Fibrosis and Palliative Care teams working closely together meeting regularly, using shared guidelines for the management of symptoms) was only described by four teams (3 above plus one smaller team). 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 understand about the meaning of Palliative Care they were offered to select from two definitions to identify 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 2\textsuperscript{nd} (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 CF and PC and they could select more than one reason for referral by their service (figure 1). 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 CF 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 symptom control. 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 CF 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 see hospital as a safe and supportive environment (Bourke \textit{et al.} 2009).
FIGURE 1: Referral Reason between Cystic Fibrosis and Palliative Care Services

Referral Reason between Cystic Fibrosis and Palliative Care Services

Referral Reason

Number of responses

0 5 10 15 20 25

Symptom Control
Psychological Support
End of Life Care
Advance Care Planning
Community Support
Support with Family Discussions
End of Life Care Pathways
Bereavement Support
Patients not referred
The newer definition of Palliative Care (WHO 2002), which teams state they currently work to, identifies an important element in addition to symptom control, psychosocial support and focus on quality of life. This relates 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 referral 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 PC too late in the disease pathway can cause distress to both patients and families (Robinson 2009). Timing of referral to PC can be viewed in Figure 2.
FIGURE 2: When is the Best Time to Introduce Palliative Care?

When is the best time to introduce Palliative Care to patients with Cystic Fibrosis?

<table>
<thead>
<tr>
<th>Time point to refer</th>
<th>Number of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early in the disease pathway</td>
<td>4</td>
</tr>
<tr>
<td>When symptoms are becoming difficult</td>
<td>10</td>
</tr>
<tr>
<td>Support in the community</td>
<td>4</td>
</tr>
<tr>
<td>Assessment for transplant</td>
<td>14</td>
</tr>
<tr>
<td>When patient is reaching end-of-life phase</td>
<td>6</td>
</tr>
</tbody>
</table>
In aiming to establish the current model of care provided, participants were invited to select a description of their current service provision between CF and PC. 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.

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. 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.

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 CF 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.
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 CF and PC. Interestingly two teams identified that they were working towards specific guidelines between CF and PC teams. Other teams identified that they worked within generic guidelines for referral to PC. As there is a lack of clarity relating to referral between the times specific guidelines may help in determining when to refer patients with CF to PC.

Respondents identified that they were completely split in terms of whether they would make any changes to working together. 50% of teams said 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. Of the teams that said they would like to make changes to the existing service. This was more likely to be raised by PC teams. However a third of CF teams commented that they wanted to increase links with PC teams. The perception here is that PC feels that although the relationship is good with CF teams the service could be delivered in another way and would like to change some elements of current the service provision.
Discussion

The findings from the survey demonstrate that there is no universal process to guide practitioners referring to Palliative Care services. There is a lack of clarity from both CF and PC services around the timing of referral of patients with CF to PC, and this is a key area for further development and will be explored further through qualitative interviews of professionals and patients. The majority of teams currently meet on an ‘as required’ basis and there are no shared guidelines to support the working practices between teams.

Although transplant has been suggested as a time point to trigger referral to Palliative Care (Focus Group 2013) the survey shows that this does not reflect current practice. For the three larger services, who reported using transplant as a trigger, they all had established a close working relationship with Palliative Care teams, reporting a fully integrated service with regular meetings. Others have advocated for effective incorporation of Palliative Care pre-post-transplant (Crone 2014) for all transplant patients and there is some evidence for efficacy of Palliative Care integration at this time point in liver transplant patients (Lamba et al. 2012).

Symptom control is a common reason for referral, although it is unclear whether this is currently occurring early or late in the disease trajectory. The symptom burden of patients with Cystic Fibrosis has been well recognised in the literature. Pain, breathlessness and cough are significant symptom problems,
with one study (Stenekes et al. 2009) reporting that 84% of CF patients had pain, 64% breathlessness and 83% troublesome cough (Stenekes et al. 2009). In addition severe nausea from antibiotic regimens is not uncommon and may lead to stopping eradication therapy. Access to palliative interventions to improve symptom control, alongside ongoing active management, may well provide opportunity for patients with CF to meet and establish rapport with Palliative Care teams early in the disease pathway, whilst gaining valuable symptom relief. Acceptability of this for patients and professionals warrants further exploration.

Difficulty in determining when to refer to Palliative Care services is reported in other studies examining the referral process between Palliative Care and patients with non-malignant disease (Ahmed et al. 2004; Partridge et al. 2009). This is in part linked to historical referral for ‘end-of-life’ and the difficulty in prognostication and identification of last phase of illness for patients with non-malignant diagnosis (Boland et al. 2013). There has been work in other groups to use a needs assessment tool in helping clinicians identify patients earlier who would benefit from additional support Palliative Care services, alongside active treatment.

Previous qualitative work with patients and families has shown that their understanding of Palliative Care is limited (Braithwaite 2011) and that CF professionals find it challenging to hold the emotional burden of caring for dying patients/families and balancing hope against death. The significant
psychological burden for CF staff who are working with patients at end-of-life, particularly pre-transplant, and jointly pursuing an active and palliative approach is well recognised (Clisby et al. 2013). Integrated working may help in further supporting CF staff at this time.

In considering the integration of services between PC and CF, several models of care are alluded to in the literature (Krause et al. 2006; Selman et al. 2007; Bourke et al. 2009; Disler et al. 2012). 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 the initial findings of this research it is clear that in practice in the UK integrated models of working are limited between CF and PC and that development of new ways of working are needed to support this group of patients (Bourke et al. 2009).
In Summary, the results of the focus group in phase 1 supported the development of the National questionnaire in Phase 2. The key issues that have emerged from the survey are

- A lack of clarity around when to refer to Palliative Care,
- Patients are referred too late
- Lack of shared guidelines to work towards and there is
- Limited integration between CF and PC teams.

Perceptions of referral to Palliative Care will be explored through qualitative interviews in Phase 3 of this study. It is hoped that in interviewing patients and professionals about their perceptions of a referral to Palliative Care earlier in their disease trajectory, that further insight will be gained to clarify what might be an effective integrated model of care for this group of patients.

**Acknowledgements**

This study was funded by the Royal Marsden NHS Foundation Trust as part of a Doctorate in Clinical Practice at the University of Surrey.
References


An Overview of the Integration of Knowledge, Research and Practice

1.0. Introduction

This section will provide a summary of the integration of knowledge, research and practice informed by undertaking this research study. The Doctorate in Clinical Practice was undertaken over a five year period and the following information will share the researcher’s personal development, and the way in which knowledge gathered throughout the course contributed to the development of the research study and professional development of the researcher.

1.1. Personal Development

The taught components of the doctorate equipped the researcher to be able to undertake the thesis and posed questions for the researcher to consider in preparing the research proposal. All elements of the Doctorate programme were enjoyed by the researcher but the taught components set the scene and highlighted the expectations for the following four years. The taught components not only aided the researcher with the research study but supported her strategically in the development of her new clinical position as a Nurse Consultant in Palliative Care. The policy development module involved the analysis of a particular policy. This assisted the researcher to consider a relevant policy in Palliative Care and consider how it had been developed, why it had been developed and by whom. Previously the researcher had accepted
policies as they were written by eminent figures within cancer and Palliative Care. This module gave the researcher the confidence to critically appraise the policy considering all aspects of its development including the cost implications and funding sources. All of the taught modules influenced the development of the researcher's thoughts and ideas for the research study. The communities in practice module helped the researcher become accomplished using U learn and being part of a dialogue with other colleagues on the programme. The Advanced Research Methods developed the thought process around different research methodologies and methods and helped in considering the epistemological stance of the researcher. The leadership programme helped not only in considering the researchers own leadership style but reviewing others style within the work place. This enhanced the researcher’s awareness in developing the research proposal and in how to consider approaching the research sites and the management of the study.

1.2. Knowledge of the Research process

The lecturers were encouraging in establishing research and ethical approval in a timely way. The researcher was encouraged by the clear guidelines regarding the process for submitting the research proposal. This in itself was a learning process regarding presenting the research study and being able to justify it being a worthwhile project. The researcher’s place of work is a specialist centre and would not normally be in the position to support a research study related to non-malignant disease. The leadership module and the Advanced Research Methods in particular helped the researcher achieve this approval. The development of the research proposal was all consuming but producing a
robust research proposal was pivotal in achieving approval at relevant committees.

The original thought regarding the research study developed as a result of reconfiguration of clinical services at the researcher’s place of work. The researcher was excited at the thought of exploring a completely different disease group in relation to Palliative Care. The researcher was aware that although not an expert in Cystic Fibrosis she was considered an expert in Palliative Care and therefore had the confidence to explore this topic. The researcher was aware that there appeared to be a number of patients with Cystic Fibrosis with symptoms that were not being referred to Palliative Care but the taught modules had informed the researcher of the need to be sure the research question was clear. As Palliative Care is so vast having a well-defined aim and research questions were critical.

The researcher met with Cystic Fibrosis specialists informally at a meeting and asked about their views on the potential research question of asking patients with Cystic Fibrosis how they felt about being reviewed by a Palliative Care service. The professionals that the researcher met informally encouraged this exploration and supported the researcher to consider researching the topic on two sites to make the findings more meaningful. In order to ensure the research sites were in support of the research study, the researcher was required to deliver a presentation to the clinical leads at both sites. This involved a power point presentation followed by a discussion. The Advanced Research Methods presentation required in the taught section of the Doctorate programme helped
structure the session and gave the researcher the confidence to ensure the
salient points were addressed. This learned skill helped secure approval for the
research study at both sites and has continued to apply this in subsequent
updates of the research study.

In developing the research methodology there were many discussions before a
final decision was concluded. Considering the research aim and questions the
final decision was to underpin the research study with a mixed method
methodology. This forced the researcher to consider her own thoughts and
beliefs about the knowledge, research and her epistemological view. In Chapter
3 of the research thesis this is explored more, but the researcher had always
perceived that she would undertake a qualitative methodology in line with her
beliefs about the world and society.

The researcher reflected on her own philosophical and ontological perspectives
and it became clear that the researcher sits naturally within a constructivist
paradigm as she believed that that the social world is unable to exist without
human beings and that social beings build their social reality (Holloway
& Wheeler 2010). The main reason for underpinning the research study with a
mixed methods methodology was to ensure that the overall aim and research
questions were answered completely and whilst ethnography was considered a
mixed method methodology was the best methodology to select. The
researcher recognised from the literature that the use of either quantitative or
qualitative alone would not answer the research questions alone and that a
mixed methods methodology would offer completeness to the research and
therefore mixed methods was the only methodology to choose (Creswell 2014). The researcher was aware from the Advanced Research Methods module that quantitative methods alone would not help understand the perceptions and meanings of Palliative Care from the participants and that qualitative research would be limited to those professionals and not generalisable to other Palliative Care and Cystic Fibrosis services.

The researcher was concerned about applying quantitative methods as previous research had always been supported by qualitative methods. The opportunity to learn skills in developing a survey and producing a questionnaire was invaluable experience not only in the development of the study but has also facilitated the researcher being able to help other colleagues in the clinical environment develop questionnaires. Applying a mixed method methodology has influenced the researcher’s critical thinking in the work place. In meetings and in developing reports a more positivist approach is noticeable. The researcher still has a more constructivist stance but now asks for more facts and figures and realises the importance of what they can contribute to research.

Undertaking the research on two sites required considerable leadership as the researcher had to plan how best to ensure the interviews in the research site in the Northern site were conducted in a timely way. The researcher learned to succinctly explain the research study to those who were not aware of the study. This was helpful in focusing the researcher on the research questions and aim of the study. The researcher was surprised at the level of support for the
research and how other professionals went out of their way to be supportive in securing rooms and privacy for the interviews to take place.

The additional workshops offered by the University relating to NVivo and Statistical Package for the Social Sciences (SPSS) were invaluable in preparing the researcher not only for the research study but in using these tools in the clinical environment. Using SPSS was a completely new way of understanding data and inputting into the programme. The researcher attended the workshop on more than one occasion and was fortunate to have a supervisor who was familiar with this programme and was able to support the researcher through this period. Constructing the spreadsheet and inputting the data was one of the most satisfying periods of the data collection and analysis.

The collection of the data was the most rewarding and interesting phase of the Doctorate. Storage of data securely and ensuring research folders were available on both sites and kept up to date was enhanced following the taught components of the Doctorate and attending Good Clinical Practice which was facilitated by the University. Learning how to secure honorary contracts at research sites and ensure research documents were secure, helped towards the researcher understanding the administration component in undertaking a research study.

Good Clinical Practice training prepared the researcher for ensuring the safety of the participants was uppermost in the researcher’s mind. Undertaking Palliative Care research can be upsetting for participants and the combination
of literature, Good Clinical Practice and taught elements of the Doctorate ensured that the participants had access to additional support after the interviews if needed.

The Doctorate has taught the researcher the importance of timelines and in essence keeping to agreed times to ensure the development of the writing of the thesis was on track. Without clear guidelines and the monthly supervision sessions the completion of the thesis would not have occurred. Learning to use the allocated time of one hour also structured the sessions so that the best use of the time available was achieved. This is an area that the researcher has applied to her own practice in terms of management within her clinical role and as a principal investigator for nursing research studies within her place of work.

1.3. Professional Development

The clinical role of the researcher was a new post at the beginning of the Doctorate programme. Having acquired the Nurse Consultant in Palliative Care taking research forward was a significant part of the role. Whilst the researcher had been successful in studying at Masters level and in publishing work she did not feel knowledgeable about the research process in depth and in the coordination of research projects out with her place of work. Encouraging other professionals to be part of research and to see the value in research was a skill that the Doctorate has supported the researcher to develop.

The researcher works within a specialist organisation where research is integrated in all aspects of care provision. Coordinating and leading a research study on research sites outside of the organisation was beneficial in considering
other research studies for the future. When invited to comment on quantitative research proposals or to critique research articles where mixed methods or a quantitative paradigm has been applied the researcher did not feel she had the knowledge and confidence to critique appropriately. In undertaking the Doctorate programme this has changed. The researcher is now more confident in presenting both qualitative and quantitative research and in the understanding of statistical information.

As the lead nurse for Palliative Care the researcher has become cognisant of the length of time needed in the planning and development stages of a research project and is fully aware of the commitment, passion and leadership required to see the research study through from beginning to completion. Being able to support other staff with research within the organisation is of critical importance for the development of the nurse consultant post.

An added learning from the Doctoral programme has been in the development of relationships with clinicians whom the researcher would normally not have come into contact with. This has established relationships that the research hopes will provide future collaborative post -doctoral research initiatives. Figure 1 below illustrates key learning from the Doctoral programme
1.4. Conclusion

It is hoped that this section has offered a concise insight into the learning that has been achieved throughout the Doctoral programme. Learning has occurred in the classroom and has been translated to affect all aspects of the researcher’s role as a clinician and a researcher. The overall aim of undertaking Doctoral studies was to contribute to the body of knowledge relating to Palliative Care and Cystic Fibrosis. The researcher believes that the Doctoral studies have facilitated this as well as providing her with the necessary skills and knowledge to continue further research studies in clinical practice.
1.5 References


1. Introduction

The research log provides insight into the development of the research study and timelines for completion. It reflects the initial thoughts behind the choice of the topic to be researched, the research to support this exploration and the evolvement of the research design.

1.1. Original Thought

In the first module the researcher was invited to map out thoughts and hopes for the Doctorate in Clinical Practice. The plan for this session was to be as creative as possible using extracts from magazines and diagrams to depict visually what the researcher wanted to achieve throughout the course. Students were advised that these would be revisited on completion of the Doctorate to see if hopes and objectives had been realised. This was the first time the researcher had considered her own personal reasons for undertaking a Doctorate. There were no pre conceived ideas regarding a research project and as the researcher was working in Palliative Care in a cancer hospital assumed this would be the area of research focus. A recent re configuration of Palliative Care services had exposed the researcher to patients with life limiting non-malignant disease. It was through the process of critical thinking and imagination that consideration of undertaking research outside the speciality of cancer and palliative evoked feelings that felt both challenging and exciting. The taught components of the Doctorate steered the researcher’s thinking regarding the choice of research subject. The first assignment allowed the researcher to
consider an influential policy document which created an opportunity to fully consider implications of Palliative Care on specialities other than cancer and to consider the issues of equity and choice regarding Palliative Care. This along with a change to the researcher's clinical practice facilitated original thought about an area of care to be developed and researched.

Spending time with the Cystic Fibrosis patients offered the researcher insight to some of the areas from which research questions could be considered. Patients seemed to be symptomatic but access to Palliative Care services seemed intermittent and focused more towards patients who were imminently dying. Considering an area of study outside of the researcher’s usual clinical practice was daunting. As an experienced senior nurse working within cancer Palliative Care the researcher had established many contacts and avenues of support. Undertaking this project demanded establishing new alliances with clinicians and researchers unknown to the researcher which although began as a challenge soon developed and created opportunities in practice. It is hoped that many of the alliances established will continue into post-doctoral studies.

This idea was further developed through sessions with supervisors and further discussions and reflections of the idea occurred with the support of clinicians in both Palliative Care and Cystic Fibrosis. Discussing potential areas of research and the thoughts of the researcher posed the development of a new skill in being able to formulate thoughts and present them in a concise way. The researcher allocated time to discuss ideas with lead clinicians from both Cystic Fibrosis and Palliative Care to aid in the development of research questions.
Comments from the clinical team were documented and considered as the research questions evolved.

Prior to writing the research proposal the researcher was invited to be part of a workshop relating to Cystic Fibrosis. This workshop facilitated meeting many different teams from the United Kingdom and discussions ensued regarding Cystic Fibrosis and Palliative Care. The presenters at the workshop were experts in their field who demonstrated the innovation and development of treatments that were now available to allow some patients with Cystic Fibrosis to live longer. Whilst the multi-disciplinary team was alluded to throughout the workshop Palliative Care was not referred to.

1.2. Identification of a Gap in the Literature

The researcher wanted to make an initial review of the literature to ensure that the area of inquiry had not previously been researched. The literature review in itself was interesting. The researcher identified that search engines, as illustrated in Chapter 3, sourced articles relating to end of life care when the terms Palliative Care were searched. The literature review revealed that perceptions of patients with Cystic Fibrosis regarding Palliative Care were unexplored and indicated that the literature that was available focused towards Cystic Fibrosis and end of life care. The literature review helped in the following ways
• Justified the research
• Ensured the research hasn't been done before
• Showed where the research fits into the existing body of knowledge
• Enabled the researcher to learn from previous theory on the subject
• Illustrated how the subject has been studied previously
• Highlighted flaws in previous research
• Outlined gaps in previous research
• Showed that the work is adding to the understanding and knowledge of the field

(Boote & Biele 2005)
1.3. Development of the Study

Following confirmation of a gap in the literature the researcher discussed with both supervisors the next steps to ensure the study progressed in a timely way. A provisional Gantt chart was developed to help guide the researcher with timelines and Good Clinical Practice Training was undertaken in 2010 and updated in 2013. The research questions were developed and refined over several iterations and are illustrated below in Table 1.

Table 1. 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 health care professionals 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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<tr>
<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>
The researcher continued to meet supervisors on a monthly basis either face to face or via Skype. Following the supervision sessions the researcher was given a synopsis of the meeting to ensure the researcher was clear on work to be achieved for the forthcoming month. The Annual Review was attended as requested and ensured that the research project was developing appropriately. Attending the planned research seminars at the University helped develop engagement with the university and encouraged the researcher to remain focused in developing the research study and stimulate her own thinking.

The development of the methodology and the underpinning theoretical model took some time to develop but with support, a mixed method methodology and a model of integrated care were agreed upon.

The data collection began April 2013 with the Focus Group which would inform Phase 1 of the study. The researcher transcribed this personally and discussed findings with supervisors. The questionnaire was developed and following ethical approval was forwarded to participants. This occurred in July 2013. The analysis of the questionnaire involved using a Statistical Package for the Social Sciences (SPSS). The researcher had support from one of the supervisors in helping to establish inputting the data, as previously the researcher had not used a quantitative methodology. Following analysis of the questionnaire the researcher planned the interviews that would inform phase 3. The planning of the interviews required more management as participants were recruited from London and central England. The researcher identified clinicians at both sites.
who would help in identifying both patients and professionals and helped in the securing of rooms for the professional interviews to take place. The researcher also had to secure an honorary contract at both sites which took several weeks but this was achieved in advance of the interviews therefore there was no time delay for this phase. The patients were offered to either be interviewed in hospital or at home. The researcher ensured that the lone worker policy was adhered to. Interviews were conducted between December 2013 and February 2014. The researcher transcribed four of the interviews and the remainder were transcribed by a recommended independent transcriber. The data analysis took several months as a number of methods had been used in applying a mixed methods methodology. All the data generated from the research study were stored on a password protected lap top.

The researcher submitted a poster presentation to the European Association of Palliative Medicine and was accepted in July 2014 in Spain. This resulted in the researcher being able to discuss with other specialists who were interested in the poster. This was of value in preparation for the Viva Voce to be able to justify the research study to experts who were unknown to the researcher. It was interesting to note that at this conference there were no other posters or presentations relating to Cystic Fibrosis and Palliative Care. An original article regarding the research study was written and submitted to the Journal of Cystic Fibrosis in 2014.

A diary and memos were kept throughout the research study and the use of Memos helped the researcher refine and keep track of ideas that developed
where incidents were compared to one another and then concepts to concepts in the evolving theory. The memos helped the researcher develop ideas about naming concepts and relating them to each other which were then illustrated in tables and diagrams for further development.

As a result of working within the clinical field of Palliative Care the researcher acknowledged what her thoughts and perceptions about the research study might be. She returned to this frequently through the development of emerging categories and themes to clarify that her own beliefs were not being imposed upon the data. The researcher also recognised the difficulty at times being in the capacity of a researcher and not being able to comment on clinical issues especially throughout the interviews.

1.4. Conclusion

This project began in January 2010 and was submitted in December 2014. The researcher developed throughout the five years in terms of critical thinking and in her views and opinions about the speciality of Palliative Care. The relationships between other students undertaking the Doctorate was helpful both for support and the formation of friendships. The process has been a challenging one, balancing a full time senior nursing post and study concurrently but the data collection was one of the most interesting, exciting times experienced. The supervisors gave their time without question and encouraged the researcher to keep going even when large amounts of work ensued. It is hoped that the overall aim of undertaking this research study which was to
contribute to the existing body of knowledge will be welcomed by others and have a positive impact on patient care.
1.5. References