

**Palliative Care Interventions in the Emergency Department; A Focus Group Study of  
Healthcare Professionals' Views**

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## **Abstract**

**Background:** Despite the national priority to reduce emergency admissions at the EOL, people with life-limiting illnesses are increasingly accessing the ED. There are however concerns that emergency care for patients with life-limiting illness is inadequate. Understanding staff perspectives of barriers to quality care provision at the EOL in the ED is fundamental in order to recommend improvements for service provision.

**Methods:** Three focus groups were conducted using semi-structured questions, based on the results of the literature review in the initial phase of the project. Purposive sampling was used as participants needed prior knowledge of palliative care or experience in working in the ED environment. Number of participants in focus groups ranged from five to nine due to workload demands within the ED on day of focus group. Data analysis was undertaken using Ritchie and Spencer's (1994) Framework analysis, providing a clear framework for the analysis process.

**Results:** ED staff identified barriers in the ED that hinder the provision of EOLC. They recommended interventions which they felt could improve care provision; patient pathway, universal documentation and improving education. Overall, participants felt the ED environment was inappropriate to provide EOLC suggesting that the primary function of the ED is not conducive to palliative care.

**Conclusion:** The ED culture does not account for EOLC presenting barriers for patients who attend for palliative emergencies. Within the UK very little attention has been paid to interventions improving EOLC in the ED. Results highlight that interventions to improve EOLC need to consider the organisational culture that exists in the emergency setting; important when considering service provision and improving healthcare.

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## **List of Abbreviations and Terms Used**

AD – Advance Directives

ACP – Advance Care Planning

COPD – Chronic Obstructive Pulmonary Disease

DNR – Do Not Resuscitate

DoH – Department of Health

ED – Emergency Department

ED CN – Emergency Department Charge Nurse

ED RN – Emergency Department Registered Nurse

EOL – End of Life

EOLC – End of Life Care

GD – Good Death

GSF – Gold Standard Framework

HCA – Healthcare Assistances

HCP – Healthcare Professionals

LCP – Liverpool Care Pathway

PC – Palliative Care

PCN/PC CNS – Palliative Care Nurses/Palliative Clinical Nurse Specialists

QOL – Quality of Life

RCP – Royal College of Physicians

RTSST – Rapid Two Stage Screening Tool (Established Interventions)

SPEED – Screening for Palliative Care Needs in the Emergency Department

WHO – World Health Organisation

## **Background**

### **1.1 Palliative and End-of-Life Care in the Emergency Department**

Emergency medicine is seen to 'treat undifferentiated patients across age and disease or injury to create time restricted assessment of the patient, to resuscitate and stabilise in order to establish initial or definitive treatment and to discharge to an appropriate facility' (Foreno et al., 2012 pg. 2). The Emergency Department (ED) can be mostly associated with "heroic" actions, life saving, resuscitation and stabilisation of patients yet in recent times it is becoming a setting that increasingly sees patients at the End-of-life (EOL) accessing the ED and treating patients with pre-existing conditions that they will eventually die from (Bailey et al., 2011b).

An increased number of terminally-ill patients are accessing the ED for care and support. Patients diagnosed with Chronic Obstructive Pulmonary Disease (COPD) currently account for ten percent of all medical emergencies in the ED (Buckingham et al., 2008) while a fifty percent increase is expected in cancer patients accessing the ED in the next ten years (Richards, 2009). It is suggested that inpatient services will have to expand by a fifth to accommodate patients needs by 2030 (Gott et al., 2013).

Terminally-ill patients are accessing the ED for a variety of reasons; symptom control, acute deterioration or exacerbation of illness and caregivers unable to cope (Lawson et al., 2008). They are also coming into the ED at the EOL where a third of patients will die in the first few hours of the admission (Yates and Barrett, 2009). Research suggests that fifty-six percent of people will die in the acute hospital setting and ninety percent of people with a terminal-illness experience a hospital admission in the last year of life (Gott et al., 2013).

Whilst there has been an increase in terminally-ill patients which is set to continue the nature of the ED has yet to change. No consideration has been given to the increasing role of End of Life Care (EOLC) in the ED environment. Many patients are seeking alleviation of distressing symptoms, comfort and support in a safe and expert environment showing a requirement for palliative and EOLC in the ED. All definitions can be found in Appendix 1.

### **1.2 The ED– Concerns Surrounding Palliative and End-of-Life Care Delivery**

The ED is a place where EOLC needs to take place because it is now viewed as a 'gateway' into hospital used when the physical, social and psychological burden of patient and caregivers maybe too high (Bailey et al., 2011; Quest et al., 2011). It is viewed as a setting in which expert care will be provided quickly and in palliative patient is viewed as a "safe environment" where they receive symptom relief (Grudzen et al., 2012a). Admission to the

ED highlights the challenges and lack of provisions elsewhere in the healthcare system that has led to the ED having to provide this care (Forero et al., 2012). Whilst care is being driven into the community, professionals in this setting face significant challenges such as limited education and training in EOLC and competing priorities (Shaw et al., 2010). Within the acute setting, there are equally significant challenges such as an emphasis on life extension and cure as well as the false assumption that HCP are educated and emotionally prepared to recognise dying patients and transfer to appropriate settings (Bloomer et al., 2011; Willard and Luker, 2006). It needs to be acknowledged that there is a wider problem that may have resulted in the ED providing this care however this study's focus remains of the ED irrespective of whether this is the right or suitable place for people at the EOL, this is the current situation and a means of organising care is needed.

Limited research surrounding this topic continually supports concerns about EOLC in the ED (Bailey et al., 2011a/2011b; Grudzen et al., 2012b; Lawson et al., 2008). Glajchen et al., (2011) refers to patients accessing the ED 'getting stuck in a revolving door' that wastes resources and fails to address the goals of care of the patient. Lukin et al., (2012) refer to those in the final stages of terminal-illness as a vulnerable population in the ED as they do not fit the 'ethos' of the acute healthcare setting. In addition, there are documented concerns when patients access the ED for support at the EOL, as they encounter problems with their expectations of fundamental care needs (Bailey et al., 2011a; Grudezen et al., 2010; Lawson, 2008). Yet the ED could aid EOLC decision-making, access and discharge, promoting holistic and individual patient care (Grudzen et al., 2012b). This could enhance quality and continuity of care experienced by patients when accessing the ED, since fewer visits to the ED during the last few months of life can be seen as an indicator to quality of life (QOL) at the EOL (Lawson et al., 2008).

### **1.3 Policy and Initiatives in End-of Life Care**

In recent years, there has been an increased amount of attention on EOLC within the UK. The End of Life Care Strategy (DoH, 2008) aimed to promote high quality EOLC, providing more choice regarding preferred place of care and setting out provisions for what a Good Death (GD) would entail. The NHS End of Life Care Programme (2004-2007) promoted and supported the Gold Standard Frameworks (GSF) and the Liverpool Care Pathway (LCP). Despite the available policy and frameworks, over half the complaints the NHS receive surround EOLC, showing improvement is still required (Milligan, 2009).

Most of these policies and initiatives have sought to move care from the acute setting into the community, statistics show a slow increase the percentage of people dying at home it is estimated that only one person in ten will die at home by 2030 (Gomes et al., 2012). Although

the intentions of policies and initiatives are to provide quality care at the EOL, little attention has been placed on the provision of EOLC in ED. The ED is a place where death frequently occurs and statistics emphasise hospitals will still be an environment where EOLC takes place, yet there is limited research on how initiatives can improve EOLC within the ED.

#### 1.4 A Call for Research

Limited research has been conducted on the subject of palliative and EOLC in the ED; it is an emerging research topic that requires more attention. Many suggest this is due to the hospice and PC medicine being newly recognised specialities where little is known surrounding how to apply current models to the ED setting (Grudzen et al., 2012b). Studies have explored clinicians' attitudes towards palliative and EOLC, common barriers in the ED associated with palliative and EOLC, reasons for admission to the ED at the EOL and during terminal-illness; however, few have explored physical interventions to improve the situation. This study aimed to explore PC and EOLC interventions that could be implemented in the ED to improve EOLC for the increasing number of terminally-ill patients accessing the ED.

#### 1.5 Research Question

A clearly defined research question and purpose can help to determine a clear search strategy for the study so literature can be searched effectively and investigators can discard unsound data (Lipp, 2007; Conelly, 2009). The research question for this study was developed using a PICOS tool which addresses all of the information needed to formulate a focussed question and discussed in terms of why it is important to healthcare (Gerish and Lacey, 2010; Stone, 2002). PICOS identifies key elements essential to a detailed research question more likely to yield a successful literature search (Stone, 2002).

**Table 1- PICOS Model for the Development of Research Question (Gerish and Lacey, 2010)**

<b>P – Populations, participants, problem of interest</b>	Staff in the ED who have experience in dealing with patients at the EOL.
<b>I – Intervention or Phenomenon of interest</b>	Interventions which staff consider could be helpful in providing care for patients at the EOL.
<b>C – Comparison or interventions</b>	Not applicable to this study as data has no measurable quality
<b>O – Outcome</b>	A summary of interventions which ED staff think could be beneficial. Exploring the positive and negative attributes of interventions.
<b>S- Study Design</b>	Focus Groups were used as the main data collection method, to obtain ED staff opinion.

## Diagram 1 -Research Question, Aims and Objectives

**Research Question – What are the views of Healthcare Professionals towards interventions to improve end of life care delivery and their use within the ED?**

### **1.7 Aims**

To explore supportive and palliative care interventions used in Emergency Departments amongst healthcare professionals

Phase 1 – Provide a detailed examination of a series of models that could be applied to the ED environment through an integrative literature review.

Phase 2 – assess the feasibility of introducing particular intervention to the ED by exploring ED staff Perception of intervention through a series of focus groups.

### **1.8 Objectives**

- To conduct integrative literature review identifying established interventions used in ED setting to improve PC and EOLC
- Conduct focus groups to explore ED providers views on interventions to improve PC and EOLC in the ED
- Explore how ED professionals' views and opinions can be applied to the ED in the UK to aid EOLC
- Suggest recommendations that could add to practice and policy to improve EOLC in the ED

## **Literature Search**

### **2.1 Introduction**

In the first phase preliminary searching identified a limited number of studies focussing on PC in the ED, some identified barriers and others practical interventions. An integrative literature review was undertaken using a systematic method to explore interventions that could improve EOLC in the ED with the intention of identifying a conceptual framework and schedule for the study.

An integrative approach was taken as it is often used when exploring emerging topics - "addressing new or emerging topics that would benefit from a holistic conceptualization and synthesis of the literature to date" (Torraco, 2005, pg. 357). Integrative reviews provide many benefits such as evaluating strength of scientific evidence, identifying gaps in current research and central issues in an area of research (Russell, 2005). Five stages were undertaken and are explained in this section problem formulation (which has been covered by the background and research question formulation), data collection, evaluations, data analysis and interpretation of data (Gerish and Lacey, 2010). A search strategy was applied to find existing literature using keywords, relevant databases and inclusion and exclusion criteria all of which address the misconception that integrative reviews are less rigorous than other types of review.

### **2. 2 Hierarchy of Evidence**

Within healthcare today, there is a need to base healthcare decisions on the best evidence available. The hierarchy of evidence suggests randomised control trials being the gold standard (Evans, 2003). This view is changing as more people acknowledge that different questions require different approaches (Daly et al., 2007). Within this thesis, due to the minimal research surrounding the topic, a hierarchy will not be used to judge existing literature as the purpose is to identify potential ideas and interventions for further development within the study.

### **2.3 Framework for Critical Appraisal**

Critical appraisal allows analytical evaluations of a study ascertaining whether the reader can have confidence in the quality of the study (Katrak et, al. 2004). Appraisal is essential in integrative reviews to ensure rigour and results can be used with confidence (Russel, 2005) The quality of the literature found will be examined within this section and the Article Summary Table (Appendix 3), considering the limitations of each study and whether this

could affect results. Bias is also considered throughout but examined more closely at the end of chapter.

The summary table has been adapted to encompass key points from each article and include key elements from the CASP appraisal tool to ensure the quality of the literature has been determined (CASP, 2001 and Gerish and Lacey, 2010). The headings have acted as prompts designed stimulate appraisal. It is important to recognise that appraisal will inevitably involve some subjective judgement on the reader’s part but this is the nature of qualitative research (Greenhalgh, 2010).

Checklists have been suggested as functional however it has been argued that this leads to a protocol driven approach detrimental to the fundamental components of qualitative research (Greenhalgh, 2010). The CASP tool has been chosen as it sets out broad questions which encompass the main principles that guide qualitative methods with fewer constraints than a checklist approach (Barbour, 2001).

## 2.4 Search Strategy

Key words are essential to any search strategy, needing to encompass all aspects of the research question so all relevant literature is located but narrowing the scope so literature found is relevant (Polit and Beck, 2006). The research question was broken down into keywords, alternative phrases and synonyms were explored and included in the search (Table 2).

**Table 2 - Key Words for Search Strategy (Adapted from Polit and Beck, 2006)**

Key Words				
Emergency Department (ED) Accident and Emergency (A&E) Emergency Services	Palliative care (PC) Terminal care PC interventions	Improve Develop Advance	End of life care (EOLC) Terminal care End of life (EOL)	Terminal illness Life-limiting illness

Keywords were put into the main electronic databases available; CINHALL, MEDLINE, AMED, BNI, Cochrane and Pro-Quest. These databases were used as they were most relevant to subject under exploration and in turn contained the most peer reviewed journals – which is suggested to improve quality of retrieved articles (Burns and Grove, 2001). After conducting searches with identified keywords (Table 2), no results were gained suggesting that the search scope was too narrow. The search strategy was reviewed; various keywords

were altered and used in different orders which retrieved relevant literature (Appendix 2 and Table 3). Different combinations were carried out to ensure that all relevant literature was retrieved.

**Table 3 - Adapted Keywords and Searches**

Adapted keywords
1. Emergency Department AND Palliative Care AND End of Life Care
2. Emergency Department AND Palliative Care
3. Palliative Care Interventions
4. Palliative Care Interventions AND Emergency Department
5. Palliative Care AND Emergency Department AND Improvement

Inclusion and exclusion criteria were applied to the literature as limiters should be applied to make the search directly relevant to project, these included naming or suggesting of specific interventions that were directly applicability to the ED and specifically focussing on improving care for those with a terminal-illness.

**Table 4 – Inclusion and Exclusion Criteria**

<b>Inclusion Criteria</b>	
Intervention or Improvement	The article must contain an improvement or intervention that can be used to improve EOLC and PC within the ED. The study must include a strategy or suggestions that could improve EOLC, as the focus groups are looking to explore Healthcare Professionals (HCP) views on ways to improve EOLC in ED and need literature review to inform focus groups.
Terminal or Life-Limiting Illness	The intervention must look to improve care for those who have a terminal-illness and are accessing the ED.
Setting	The study must consider the strategy with direct applicability to the ED setting and to be used within the ED setting.
Date	There will be no date exclusion as little research has been done on this topic and only recently has it been looked at acknowledging that action needs to be taken.
Type of Literature	All literature will be used as minimal research has been done on interventions or strategies to improve EOLC. This includes grey literature, unpublished literature, thesis, dissertations and conference papers all included in database searches. Even though this was in the inclusion criteria no grey literature was used or any relevant theses found that explored models to improve EOLC in the ED.

<b>Exclusion Criteria</b>	
Non-Intervention	Need strategies to inform the study, whilst literature has highlighted problems, physical interventions are required to gauge whether these would be suitable to place in UK ED's.
Traumatic, sudden other types of conditions	As previously stated the approach to patients at the EOL is different to the approach with traumatic and sudden deaths experienced in ED. These types of death and patients are frequently researched, unlike those with terminal-illness accessing the ED.
Setting	Excluding any articles which are not looking specifically at strategies to implement within the ED. Some studies have looked at what can be done in other settings to reduce admissions to the ED however within this study the aim is to consider how care can be improved if admission is necessary.
Date	No date exclusion as initial searches suggest that this particular area has not received much attention.
Type of Literature	All literature will be used as initial searches suggest that this particular area has not received much attention.

As well as subject specific electronic databases, relevant journals, references, Google scholar and Library resources were searched using the same combinations of keywords (Appendix 2). This achieved a wider scope of the literature ensuring that all relevant data is gathered (Greenhalgh, 2010). Several articles were excluded as the interventions were not placed within the ED but in other settings looking to prevent admission to the ED, others focussed on EOLC of patients coming in with traumatic injury, not relevant to this study. After the inclusion and exclusion criteria had been applied eight articles were found to be relevant, seven within databases and one through reference searching (Appendix 3). Articles excluded have been read and used throughout the study to outline the problem, justifying why this research is essential.

## **2.5 Bias**

Bias has been accounted for within the literature search by applying a thorough search strategy that has been documented comprehensively (Appendix 2-3). A comprehensive literature search is crucial to identifying the widest range of literature available (Polit and Beck, 2006); in turn this informed the research and the semi-structured interviews of the focus groups. Searching was a continuous process until a saturation point was reached where no new articles were found. Additionally, frequent searches throughout the project

were done on all databases to ensure no new research had become available or missed. One other study by Paterson et al., (2009) was found during this process that looked at implementing the modified Liverpool Care pathway (LCP) into the ED, which has been used in the discussion to support findings from this study. The literature scope was reviewed by the research team discussing content to limit personal bias from primary researcher. Throughout there is reference to the research team this encompasses both supervisors who have knowledge and understanding of the project as well as knowledge and interest the research field. They acted as observers in the focus groups and oversaw the analysis process providing guidance throughout the project.

## **2.6 Literature Search Findings**

A total of eight articles were found to be relevant (Appendix 2); two of which reported results from focus groups to explore views on EOLC in the ED (Smith et al., 2009; Beckstrand et al., 2012a), two feasibility studies of assessment tools (Richards et al., 2011; Glajchen et al., 2011) three narrative commentaries on improving EOLC care in the ED (Clarke, 2008; DeVader et al., 2012; Grudzen et al., 2011) and one manuscript from a conference looking at improving quality and efficacy of the ED (Quest et al., 2011). The key ideas from the retrieved articles were explored leading to the development of themes which will be discussed further. A total of five themes were identified; barriers preventing good EOLC in the ED, improvements in communication and documentation, further education and training in PC, palliative specialists being present in the ED and the need for an appropriate tool to identify patients at the EOL. A summary will be provided of the themes however the main focus is on the assessment tools and interventions as these are the main contributors to the framework of this study.

## **2.7 Barriers**

Barriers that prevent optimal EOLC within the ED were identified in all the articles, often divided into attitudinal and structural barriers. Structural barriers involved the design of the ED leading to fragmented care and lack of privacy at the EOL due to no private rooms, constantly moving and different sections within the ED (Smith et al., 2009; Clarke, 2008; Glajchen et al., 2011). The environment within the ED was seen as chaotic with HCP having a heavy workload suggested not to be conducive to providing good EOLC (Smith et al., 2009). On top of this was the prioritisation of patients that are acutely unwell and the competing demands of dealing with other patients coming in (Smith et al., 2009; Beckstrand et al., 2012a). Attitudinal barriers documented were the lack of medical history and pre-existing relationships with the patients (Glajchen et al., 2011; Smith et al., 2009; Richards et al., 2012, Beckstrand et al., 2012a), frequently making it difficult to assess the patient's

current goals of care. Furthermore this was exacerbated as patients were acutely unwell, unable to give information about their condition and express their wishes (Grudezen et al., 2011; Glajchen et al., 2011; Smith et al., 2009).

## **2.8 Documentation and Communication**

Inadequate documentation was often identified as a barrier to preventing good quality EOLC in the ED; on admission there is often no previous history available, no documentation of goals of care, no documented wishes in extreme circumstances e.g. resuscitation and no communication from primary physician available to assist HCP in appropriate treatment and care (Smith et al., 2009; Grudzen et al., 2011). Mistaken resuscitation had happened as a result of inadequate documentation and if instructions were present, in some situations there was too much discrepancy in what 'comfort measures only' means (Smith et al., 2009). Richards et al.(2011) and Smith et al.(2009) reported that ED providers found it difficult to have conversations with patients and relatives when they had not met them before especially on EOLC issues. All articles suggested a need to improve documentation and communication between primary care providers and the ED as well as improved documentation in the ED. A limitation that needs to be acknowledged is that these studies were conducted in the United States therefore Advance directives (AD) were used throughout the literature which is not a familiar concept in the UK.

## **2.9 Education and Training**

HCP considered increased training in communication as essential, specifically in ability to discuss care at the EOL. They believed this would help to improve confidence when discussing these issues which in turn could help in educating patients and families about care and expectations at the EOL (Beckstrand et al., 2012a). Both doctors and nurses felt they had insufficient knowledge in regard to managing palliative patient's pain and training in pain management was essential to improve EOLC. Glajchen et al.,(2011) found that PC is under used within the ED due to a misunderstanding of what it actually entails.

## **2.10 Palliative Care Champions**

To maintain good EOLC many suggested PC champions to be present within the ED or consultation services to be available (Glajchen et al., 2011; Grudzen et al., 2011). Champions would be seen as 'experts' that educate and support other HCP in PC provision and EOLC in the ED (Clarke, 2008).Glajchen et al.,(2011) positioned PC nurses in the ED which was fully embraced by nursing staff with positive feedback and increased identification of patients requiring PC (Glajchen et al., 2011). Grudzen et al.,(2012) found the

implementation of palliative champions in ED reduced length of stay as patients were referred to more appropriate facilities or care settings. Others suggested instead of PC champions, hospice nurses assist with palliative and EOLC needs within the ED (Grudzen et al., 2011). Caution needs to be applied as the studies took place within the US where different systems are in place such as PC units within the hospitals, where many of the patients in these studies were referred.

### **2.11 Identification and Assessment of Patients at the End of Life**

A system to identify patients in need of palliative or EOLC was seen as pivotal to improving EOLC in many studies (Richards et al., 2011; Glajchen et al., 2011). A screening tool would assist in identifying people with unmet needs within the ED and referring to appropriate services whether this is community services, in-patient or a follow-up. Richards et al.,(2011) suggests an assessment tool could be useful to effectively identify and assess patients' PC needs, needing to be easily understood by both patient and HCP. At present no tools have been developed in line with the unique nature of the ED, the current tools have been developed in oncology and PC settings where care and available time is different to the ED.

### **2.12 Rapid Two-Stage Screening Tool (RTSST)**

Glajchen et al.,(2011) developed a tool (RTSST, Diagram 2) to identify unmet PC needs in patients over sixty-five with terminal-illnesses admitted to the ED, alongside the placement of a social worker, PC champions, a streamlined referral process and outlined criteria required for referral. Patients who were referred, reported decreased symptoms such as shortness of breath, pain and nausea compared with those who were in the non-referral group (Glajchen et al., 2011). The tool helped to refer patients to more appropriate places of care increasing use of hospices and inpatient PC facilities. Limitations within this study were the failure to acknowledge those with PC needs under sixty five and due to study being conducted in the US different systems and facilities are in place which may affect the applicability to tool in the UK. Aside from this the project was successful and identified patients palliative needs showing improvement in their care, staff responded to the tool with PC champions advocating PC.

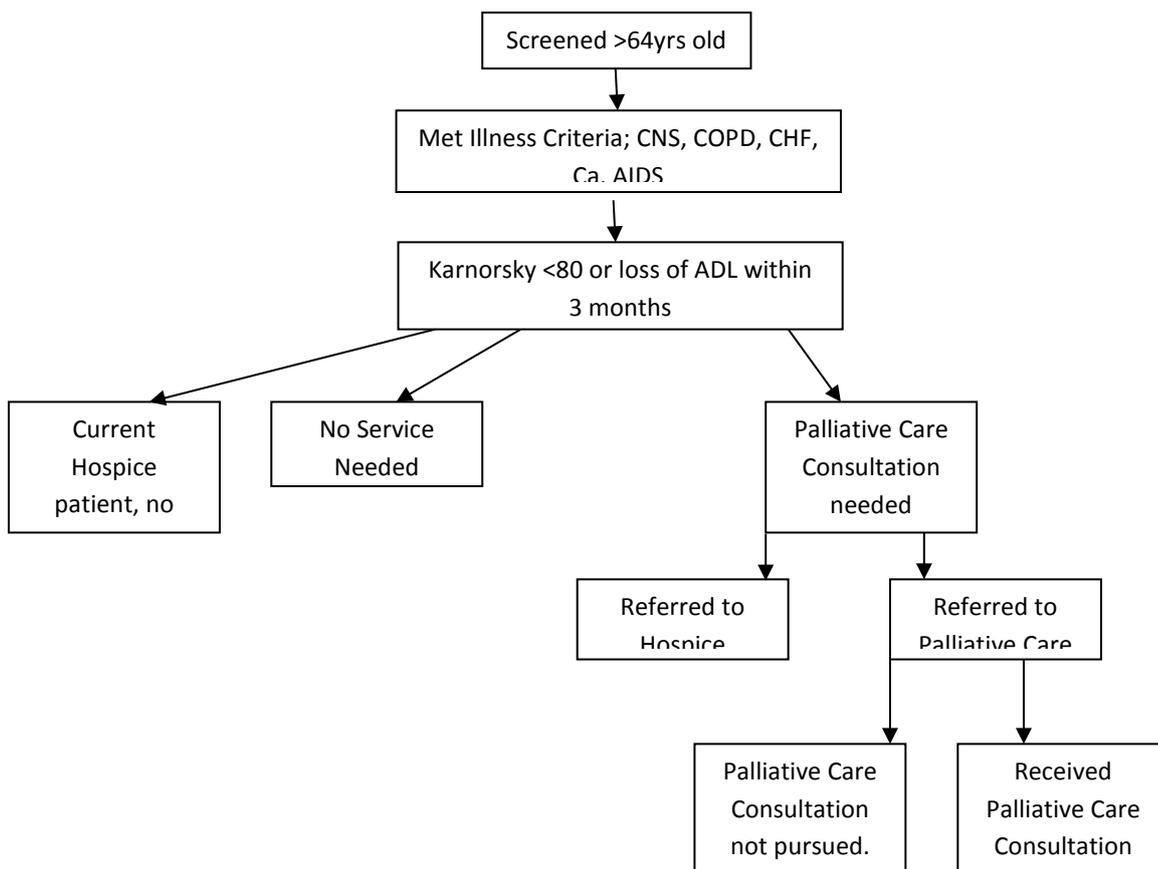
**Diagram 2 - Rapid Two Stage Screening Tool (Glajchen et al.,2011)**

**Stage 1** – Patients with specific life limiting conditions (COPD, Chronic Heart Failure, Advance malignancies, dementia and AIDS) with at least moderate functional status limitations were referred to palliative care.

**Stage 2** – Subgroups with recent losses in Activities of Daily Living (ADL's), high symptom distress, poor functional status and high level care giver burden were referred to palliative care.

- Both sets of patient were then referred to palliative care and if appropriate had palliative care input with referrals to hospice and support in community if required.
- In conjunction a laminated card of referral criteria was installed and displayed and a referral hotline was installed.

**Diagram 3 - Flow of Patient Recruitment Within RTSST (Glajchen et, al. 2011 pg. 69).**



## 2.13 Screening for Palliative Care Needs in the Emergency Department (SPEED)

Richards et al.,(2011) investigated the tool which was developed by emergency and palliative medicine experts for specific use within the ED (Table 5). The SPEED tool is intended to be used with oncology patients presenting to the ED, identifying any PC or EOL requirements and comprehensively assessing these needs. The purpose of the tool was to provide better assessment than previously validated tools and for specific use within the ED unlike other tools currently used. The validation of the tool included comparisons against the Needs at the EOL Screening Tool (NEST) currently used in palliative medicine (Appendix 4). The study indicated it is a valid tool to comprehensively assess oncology patients PC needs presenting to the ED. Whilst it is the only tool developed for use in the ED its is limited to those with terminal advance malignancies. Richards et al.,(2011) suggest further research is required to explore the effectiveness of the tool in identifying palliative needs of non-cancer patients.

**Table 5 - SPEED Tool (Richards et al., 2011)**

<b>SPEED Tool</b>
<b>Social</b>
<ol style="list-style-type: none"> <li>1. How much difficulty are you having with your medication (for example, obtaining medications, knowing how or when to take them, managing side effects)?</li> <li>2. How much difficulty are you having getting outpatient follow-up (for example, transportation, arranging, making or forgetting appointments)?</li> <li>3. How much difficulty are you having getting your care needs met at home (for example, bathing, dressing, and meals)?</li> </ol>
<b>Therapeutic</b>
<ol style="list-style-type: none"> <li>1. How much difficulty are you having communicating with your doctors about your care preferences?</li> <li>2. How much difficulty are you having with the care your clinical team is providing?</li> <li>3. How much difficulty are you having getting medical care that fits with your goals?</li> </ol>
<b>Physical</b>
<ol style="list-style-type: none"> <li>1. How much are you suffering from pain?</li> <li>2. How much are you suffering from shortness of breath?</li> <li>3. How much are you suffering from other physical symptoms?</li> </ol>
<b>Psychological</b>
<ol style="list-style-type: none"> <li>1. How much are you suffering from anxiety?</li> <li>2. How much are you suffering from depression?</li> <li>3. How much are you suffering from feeling overwhelmed?</li> </ol>
<b>Spiritual</b>
<ol style="list-style-type: none"> <li>1. How much does this illness seem senseless or meaningless?</li> </ol>

## 2.14 ABCD Assessment

DeVader et al.,(2012) acknowledges that an assessment tool could be useful within the ED to guide care of those at the EOL, presenting an tool which can be used on admission to the ED for patients requiring palliative assessment and EOLC (Diagram 3). DeVader et, al (2012) suggests using the ABCD Assessment after initial ABCD, providing HCP with an overall view of the patient and what can be done to help them in turn improving EOLC. This assessment takes less than two minutes to complete entailing important factors guiding good EOLC in addition to prompting discussion, communication and comfort of patients (DeVader et al., 2012). Whilst decision making capacity on this tool is one of the last elements to be discussed in England by law under the Mental Capacity Act, 2005), this would have to be one of the first things to be assessed and discussed.

### Diagram 4 - ABCD Assessment (DeVader et al.,2012)

- A) Does the patient have any **Advance Directives** in place regarding life sustaining treatment measures? If so what are they?
- B) How can you make the patient feel **Better**? This symptom management phase of the acute resuscitation while HCP decides level of resuscitation required.
- C) Are there **Caregivers** at the bed side? If not how can they be contacted? If there are how can their needs and desires be considered?
- D) Does the patient have **Decision-Making-Capacity**?

## 2.15 Literature Limitations and Methodological Considerations

Whilst some limitations have been identified whilst discussing the tools, there are other limitations surrounding the studies which will be explored in this section and further critique can be found in Appendix 3. The limitations identified within the study have aided this research and have been taken into consideration in the development of the framework for the study.

**Table 6- Summary of Interventions**

Author	Interventions	Strengths	Limitations
Glajchen et, al. (2011)	Rapid Two Stage Screening Tool (RTSST)	<ul style="list-style-type: none"> <li>• Study was able to show improvement due to interventions put in place.</li> <li>• Identified barriers</li> <li>• Demonstrates that PC and ED medicine operate differently but collaboration can occur.</li> <li>• Considered those not only with malignancies but non-malignant disease such as CHF and COPD.</li> </ul>	<ul style="list-style-type: none"> <li>• Only looked at patients over 65 when demographic for those receiving PC is much more varied.</li> <li>• Referrals decline when social worker was not present.</li> <li>• Undertaken in the US where there is different healthcare structure</li> </ul>
Richards et, al. (2011)	Screening Palliative care needs in the Emergency Department (SPEED)	<ul style="list-style-type: none"> <li>• Tool deemed to have face validity.</li> <li>• Previous tools developed in oncology and PC separately. SPEED developed by emergency medicine and palliative specialists.</li> <li>• Is designed to be used by the MDT</li> <li>• Promotes holistic idea fundamental to PC.</li> </ul>	<ul style="list-style-type: none"> <li>• Only applies to Cancer patients – not tested on those with non-malignant disease.</li> <li>• Undertaken in the US where there is different healthcare structure</li> </ul>
DeVader et, al. (2012)	ABCD assessment	<ul style="list-style-type: none"> <li>• Explores palliative care implications on not only patient but family.</li> <li>• Includes ‘key features’ of what people perceive to be helpful when first meeting someone at the EOL.</li> </ul>	<ul style="list-style-type: none"> <li>• Order of questions would have to change as in the UK whether a patient has decision making capacity is essential by law.</li> <li>• Undertaken in the US where there is different healthcare structure</li> <li>• No validity undertaken on assessment tool.</li> </ul>

Internationally, several studies have been conducted showing implementation of interventions to the ED (Richards et al., 2012; Glajchen et al., 2011; DeVader et al., 2012) as well as suggestions on how it could be improved (Smith et al., 2009; Beckstrand et al., 2012a; Quest et al., 2011; Grudzen et al., 2011). Whilst these studies have limitations and are not necessarily applicable to the UK due to the fundamental differences in healthcare structures and systems where they were conducted, they provide an overview of established interventions that can be presented within the study to explore further interventions that could be implemented in the ED in the UK.

The literature search also had methodological influence in the sample, method and what would be explored in the study. The appraised studies used various patient groups, Richards et al.,(2011) focused only on oncology patients, Glajchen et al., (2011) looked at patients

under sixty-five. However within this study it was chosen to consider the complete patient group to gain a more detailed insight of the situation involving all patients as many people accessing the ED are over sixty-five and have other life-limiting conditions other than cancer (Gott et al., 2013). Beckstrand et al., (2012a) used only ED nurses from one agency within sample which was felt to be too narrow whilst in contrast Smith et al., (2009) used physicians, nurses, social workers, technicians and academics. It was felt from this that HCP who provide the care directly would be included in sample as they would be the front line staff using the interventions or providing the care.

Whilst each of the studies adds to the present body of knowledge none present a complete picture of the current situation and all the options available. The literature search has provided a complete picture of what interventions are present in the ED and will be presented to participants so in-depth results can be gathered whereby participants are aware of interventions presently used.

### **2.15 Summary**

The main themes from all the articles have been discussed and used to inform and develop the semi-structured questions for the focus group as well as a basis for focus group discussions. The focus group aim is to explore ED professional's views on the interventions and how they can be used in the ED to aid EOLC.

## **Method**

### **3.1 Introduction**

Phase one highlighted what is already known and will be used to inform phase two in data collection. A qualitative approach has been taken; "Qualitative research is an inquiry process of understanding a social or human problem with distinct methodological tradition. The researcher builds a complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in a natural setting" (Creswell, 1994, pg.145).

Qualitative research generally uses an inductive approach to discover patterns which emerge after close observation, careful documentation and thorough analysis where theory is developed or pattern of meaning is observed in data collected. It must be this acknowledged that this process of discovery is basic to the philosophical underpinning of a qualitative approach (Creswell, 2012). It is associated with social constructivist paradigm with emphasis round the socially constructed nature of reality, this approach enables researcher to gain in-depth and complex understanding of peoples experiences producing contextual findings required for this study (Gerish and Lacey, 2010).

Another benefit of the qualitative approach is it generates understanding, useful in subjects where little existing research has been conducted (Greenacre, 2003; Stewart et al., 2007). The approach whilst being methodical it allows for greater flexibility in data collection than other approaches (Creswell, 2012). This section justifies method choice considering strengths and how limitations can be overcome, the development of the methods is outlined alongside processes for data analysis and bias being considered throughout the data collection process.

### **3.2 Data Collection Method**

Focus groups were the chosen data collection method as they provide an in-depth account of the phenomenon under investigation in this exploratory study. The choice was also influenced by previous studies that used this method as they gained a more detailed account of the topic through discussions and participants being able to explain their response (Stewart et al., 2007). Group discussion is particular important when open questions are being used and researcher encourages participants to explore what is important to them (Kitzinger, 1995).

This method permits the researcher flexibility with questions and therefore discussions within the group, a useful characteristic within this project where there is limited existing research (Hudson, 2003). For this reason focus groups were favoured over other methods

as they can help people to explore and clarify views in a way that would be less accessible in one to one interview (Kitzinger, 1994). In addition they can encourage participation from those reluctant to be interviewed alone, but will engage in discussion generated by other group members. Interpersonal communication is another advantage of using focus groups and important as it can highlight cultural values and group norms not available through other methods (Shaha et, al. 2011).

Focus groups have become increasingly popular within Palliative Care (PC) research, as the interaction between participants offers detailed findings regarding their experiences and feelings towards the topic another reason for this method choice (Perkins et al., 2007).

The limitations of focus groups will be considered throughout the process (Kitzinger, 1995), factors considered were, the influence of bias, which will be discussed at the end of the section, as well as factors that may negatively affect group dynamics. It was noted that when conducting focus groups the results may not be reflective of the larger population, however the purpose of the study was to explore an under-researched topic providing meaning and understanding rather than generalising findings. Therefore it is felt the issue of generalisation does not limit the value of this study.

Three focus groups were conducted, the first of which was called a 'pilot' group. Qualitative data collection is flexible in nature and often the method is adjusted as the study develops to explore and gain further insight. The first group was labelled a 'pilot' group for several reasons; firstly, it included a variety of HCP including PC nurses not involved in any further groups. Secondly was used to develop and test questions addressing any misunderstanding of any topics involved (Shaha et al., 2011). It was suggested that data saturation can be aided by carrying out a pilot group as the moderator can better understand participant fatigue and when similar topics are covered developing strategies avoid this (Cote-Arsenault and Beedy, 1999).

Key points and a summary were produced after each focus group and development shown throughout; Raibee (2004) suggests this improves analysis and whether sufficient data was collected. The data from the 'pilot' group was included with caution in the analysis as Holloway (1997) suggests whilst qualitative data collection is a progressive process, the pilot helps to improve subsequent interviews it can also offer valuable insight. There was also a limited time frame to collect the data, with a maximum of three focus groups therefore to ensure meaningful conclusions 'pilot' group data was used. Ideally more groups would have been conducted however this was not possible and 'pilot' group data was used with caution and acknowledged that group had a slightly different make up than subsequent two focus groups.

### 3.3 Sample

There is no optimal number of focus groups; however number of participants in each focus group and composition of the focus groups can have important effects on results (Stewart, et. al, 2007). Sizes of groups vary from five to twelve participants with the optimal being considered four or five participants; this allows diversity within the group and is small enough allowing each member to fully explain their views and experiences (Shaha et al., 2011). Sample size for each focus group was kept at between six to eight participants thus allowing for over-recruitment.

Purposive sampling was used, whilst there is divided opinion regarding sampling in focus groups, the sample reflects participants' need to have prior knowledge of PC or worked in the ED for meaningful and relevant discussions to take place answering the research question (Cote-Arsenault and Beedy, 1999; Morgan, 1997). The decision was made to include nurses, Health Care-Assistances (HCA) and PC nurses in the same focus group however after the pilot group it was decided that the presence of PC nurses changed the focus of discussion. It was felt that it became an education session surrounding PC services in the hospital, referral to PC and how the PC team work rather than focussing on how the situation could be improved in the ED. The debrief and further comments surrounding this can be found in Appendix 9.

The two remaining focus groups contained ED nurses and HCA's with a separate key informant meeting with PC nurses to develop the quality of findings. Other factors that may influence discussions were age, education, and hierarchal position however it is the role of the moderator to facilitate and guide equal and fair discussion ensuring contribution from everyone (Shaha et al., 2011). Participants' individual contributions were identified through use of numbering system e.g. ED Nurse 1, Charge Nurse and during the analysis process voice recognition was used which is why the transcription was completed by the researcher present at the focus groups ensuring correct identification.

The sample may contain bias towards the research topic due to all HCP being involved in the topic of the research however the specific specialities are required to make the results meaningful.

Recruitment was achieved by contacting managers within the ED and PC team, gaining their support, helping to publicise the project to maximise recruitment. The managers in the ED took on the role of recruiting participants, this approach can be seen to assist with sample bias on the other hand can be seen to induce bias by the pressure of senior figures asking participants to attend however we feel this has been overcome by the repetition of the focus

groups (Kruger and Casey, 2000). Location is essential as it can influence people's ability to participate (Cote-Arsenault and Beedy, 1999); focus groups were conducted at the hospital where recruitment was undertaken and close to the ED so it was easily accessible.

### **3.4 Planning Focus Groups**

Prior to conducting focus groups it was recommended to develop an interview guide as this would be useful in directing and enhancing group discussions (Shaha et al., 2011). The recommended number of questions was twelve; however studies (Stewart et al., 2007; Kitzinger, 1995) found fewer questions easier to cover, allowing everyone to contribute. A semi-structured interview guide was developed (Appendix 5) and as Kruger and Casey, (2000) suggested the focus group started with simple and neutral questions that would get participants to examine EOLC in the context of the ED. This allowed the group to settle into the discussion naturally progressing onto more specific topics allowing for probing to gain further clarity and insight. Open questions were used to elicit a full response from participants gaining their own opinions and experiences. Whilst interventions remained the focus of the discussion by building up to this and exploring experiences it was felt participants may reflect on own experiences and how interventions could have improved these or applicability to those situations.

The literature search was used to develop a hand-out (Appendix 6) to gain ED professionals' views on strategies that already exist to improve EOLC. Group exercises and activities can be used to explore understanding or indicate preferences encouraging participants to focus on one another rather than taking lead from the moderator further stimulating discussion (Kitzinger 1994; Gerish and Lacey, 2010). The handout was reviewed by the research team, PC team and managers within the ED where their understanding and feedback were gained, with appropriate changes being made. Most focus groups last between one and half hours to two and half hours before participants become fatigued and overloaded with information (Stewart et al., 2007), the discussions last approximately an hour. The groups were recorded digitally with all technical aspects being considered and were available to access at point during transcription and analysis (Gerish and Lacey, 2010).

An observer was present, to manage recording, monitor group interactions and record any observations such as non-verbal behaviours which would be used to facilitate analysis, recall specifics and could be accessed at any point during analysis, although observers were not directly involved in analysis. It was a methodological decision to have the presence of an observer, providing insight into group interactions as studies show this is helpful (Barbour, 2008; Maclafferty, 2004). The observer was part of the research team as they had an existing knowledge of the project but did not participate in discussion. Different observers were used,

asked to note key points that could be used in analysis. Using different observers gave a more varied analysis and less bias as neither had been present in previous groups.

An effective and competent moderator is essential to a successful focus group (Kitzinger, 1994). They must gain the trust of the group, conduct sessions efficiently with confidence and knowledge of the topic, being able to guide and facilitate discussion remaining neutral. Barbour (2008) suggests it is useful to have two moderators within a focus group to overcome lulls in discussion or problems with participants, however if smaller groups are being used it may hinder the flow of discussion. The researcher undertook the role of moderator due to pre-existing knowledge of topic and understanding of interventions, an interview guide and observer was used to limit researcher bias over the focus groups (Gibbs, 1997).

### **3.5 Ethics**

Ethics approval was sought and approved prior to conducting the study through submission of a research protocol to the research and development department at the Trust where the study was conducted (Appendix 7 and 8). Ethical issues considered pertain to confidentiality, consent and disclosure (Owens, 2001). Confidentiality was promoted throughout the groups, whilst discussion had in the groups were confidential if there were any concerns of professional codes of conduct being breached this would have to be addressed. Whilst it needs to be acknowledged that this approach may have made participants less honest in fear of whistle blowing, there is a duty of the researcher to ensure practice is safe and report concerns (Kruger and Casey, 2000). Nevertheless throughout the groups it was felt by the moderator and observer that discussions were honest and open about the current situation in the ED.

Within qualitative research, specifically focus groups the analysis process can be more difficult to keep confidential as direct quotes are used to support findings where potentially the identity of the participant could be shown. This was minimised by pseudonyms being used during the transcription and within the analysis. Consent within qualitative research is seen as continuous process, gained at the beginning of the focus groups and making participants aware they can withdraw at any point if any concerns arise as a result of their participation (Shaha et al., 2011).

Within focus groups that deal with sensitive subjects such as PC and EOLC, the data obtained can reveal personal details, drawing on the individuals' experience and it is advised that mechanisms be put in to manage the issue of distress or anxiety if it occurs (Owens, 2001). The moderator was to use their own discretion to assess the situation and best

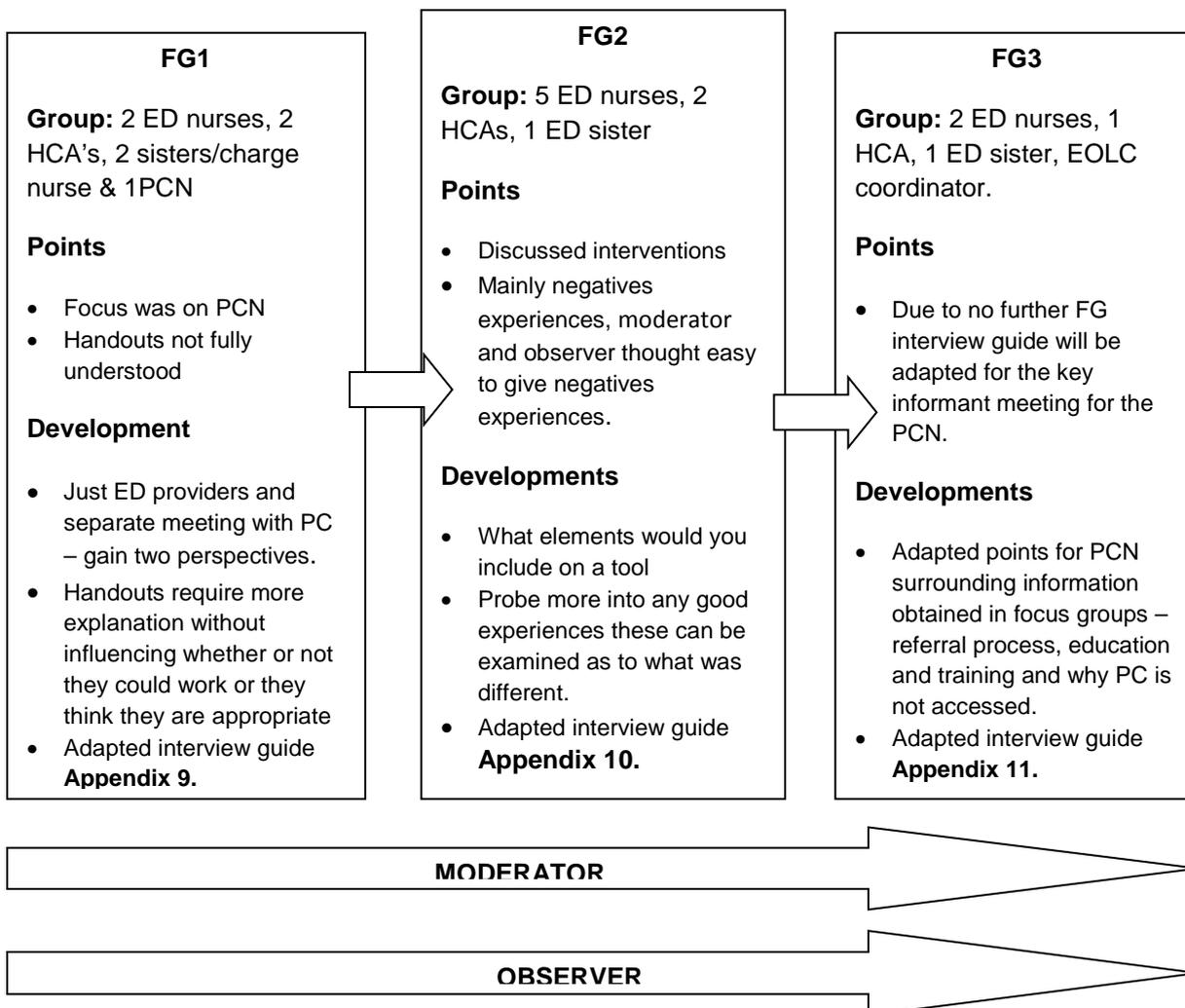
course of action if these issues did arise, whether to continue, pause and resume when participant is present and feels able to continue or has withdrawn.

### **3.6 Focus Group Development**

The moderator concluded each focus group with a closing statement formally ending the group by summarising discussions and clarifying key points, this is said to aid validity of results but also assist in gaining an understanding of them, embarking on the first stage of analysis (Shaha et al., 2011). Additionally the moderator and observer at the end of each focus group conducted a debrief to ascertain the comprehension of topics covered, ensure data collected was sufficient and record initial observations. The strength of a debrief was that it can be seen to limit researcher bias as initial analysis is conducted with another member of the research team. Moreover it was used to reflect on focus groups and the insights gained could improve subsequent interview schedules and questions (Holloway, 1997).

One of the main remarkable developments throughout the focus group was the attention on the handouts, it was thought in the first focus group participants did not fully understand interventions therefore in further focus groups more explanations surrounding the interventions were given. Other developments were focussing on if interventions were felt no to be appropriate exploring other options or what elements participants thought were of use on the interventions and other elements that could hinder its application in the ED. Development has been documented throughout the research process (Diagram 4, Appendix 9-16), providing an evidence trail so the reader can be assured of the study's validity and therefore transferability (Parahoo, 2006).

**Diagram 5 - Focus Group Development**



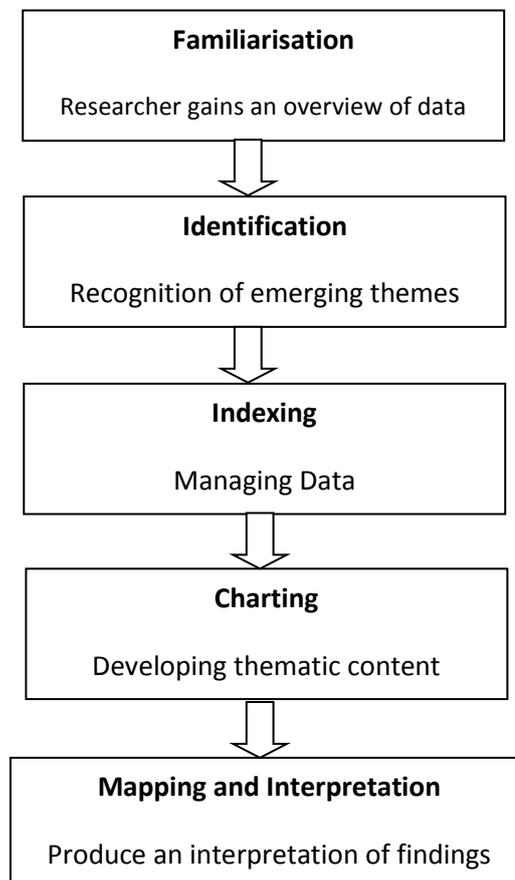
### 3.7 Data Analysis

Analysis and interpretation of focus groups needs a great deal of judgement, there is no consensus as to the best way to analyse focus group data which is mainly dependent upon the research question and purpose (Webb and Kevern, 2010). Some of the scepticism surrounding focus groups originates from the perception that data collected is subjective and difficult to interpret. The analysis and interpretation of data can be rigorous as for data generated by any other method, analysis should be viewed as ‘verifiable, sequential, continuous and systematic’ (Kruger and Casey, 2000, pg. 128). It is a planned process that is constantly evolving to ensure results reflect the discussion, a systematic approach has been implemented, and documenting all processes to ensure it is understood and easily interpreted by others. It requires independent readers to reach the same conclusions using the same sources, this ensures verifiability, which Gerish and Lacey (2010) suggest is a

critical safeguard in focus group analysis. In order to achieve a sufficient evidence trail, evidence must be present from the interview guides to progression of data analysis (Appendices 6-21).

Raibee (2004) suggests analysis and data collection are carried out concurrently as it improves future data collection and sufficient data is collected, therefore analysis started when the first focus group was conducted. The data analysis method used was Ritchie and Spencer's (1994) method of Framework Analysis which includes the five stages of analysis (Appendix 12).

**Diagram 6 - Overview of Spencer and Ritchie Framework Analysis (1994) (Full Framework - Appendix 12)**

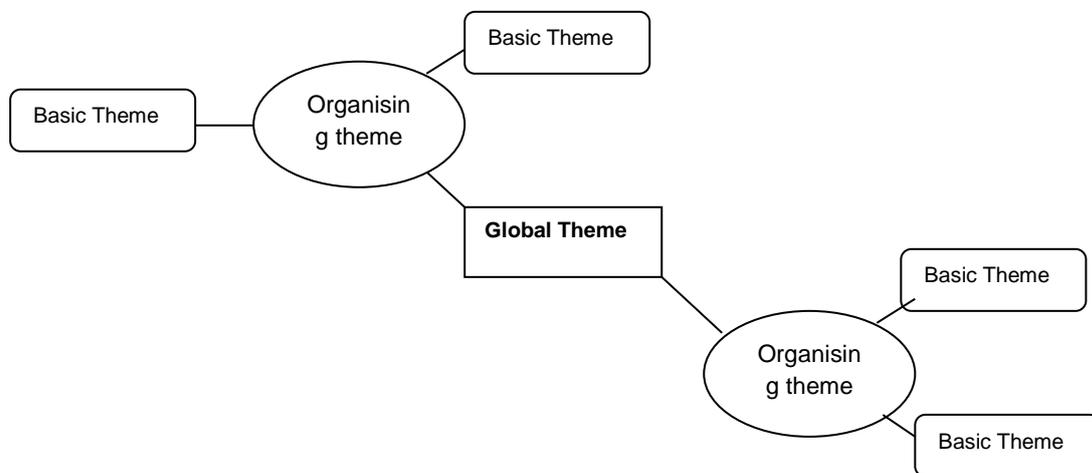


This approach is built on thematic analysis but offers a framework to ensure analysis is carried out in systematic manner presenting a clear view of the process (Dixon-Woods, 2011). Ritchie and Spencer's (1994) framework analysis main aim is to describe and interpret what is happening by providing a clear and comprehensive set of steps for analysis that are accessible to be viewed and judged by others (Srivastava and Thomson, 2009).

Another advantage to this method is that it is dynamic, allowing change or amendment throughout as qualitative analysis is not a linear process (Kruger, 1994).

Thematic network analysis has been used as an “organisational tool for the researcher to manage data and for the reader to see the process of data analysis” (Attride Sterling, 2001,pg.387). Kruger and Casey (2000) suggest a strategy is used to undertake this process due to the amount of data collected. Thematic network analysis is a simple way to organise thematic data, providing an organisational structure to present and unearth themes. It has been used to show each of the focus groups basic themes (codes) and organising themes (themes) and Global Themes (Overarching themes) (Appendices 14-16).

**Diagram 7 -Structure of Thematic Analysis Network (Attride Sterling, 2001)**



The analysis process was started by following Ritchie and Spencer’s (1994) Framework Analysis, firstly reading the transcripts, gaining familiarity of the text and participants’ responses. Following that, keywords were assigned to each sentence or response that summarised what the participant said which achieved the indexing and coding section of the framework analysis (Kruger and Casey, 2000). Initial codes or basic themes were developed from this and shown in Appendix 13. The transcripts were re-read and codes considered which then lead to grouping codes into organising themes after considering the frequency in which the codes appeared in the text and similar codes that could be compared within each focus group. At this stage due to the volume of data collected it was seen as beneficial by the researcher to analyse each focus group individually creating a thematic network analysis map for each focus group using Attride-Sterlings (2001) Thematic Network analysis to organise data and present to the reader in way which they can view development of analysis (Appendices 14-16). The next stage was to compare the groups where overarching themes became apparent which are discussed in the main findings and discussion. The process was

repeated with the transcripts being re-read to ensure all data had been considered and the themes were reflective of the data. At each stage of the analysis the data was reviewed by the research team and themes discussed and considered to ensure that results were replicable and valid.

Considerations made within the analysis stage were problems with transcription such as changing spelling of words, missing words and participants' responses not making sense. By altering these errors the researcher is directly altering responses and offering their own interpretation of what the participant was saying (Webb and Kevern, 2001), for this reason it was left as what was originally said. The non-verbal communication is sometimes not included in transcripts however it is felt including this may enhance analysis and in turn provide further insight into participant's views.

### **3.10 Bias**

Bias can affect the validity of the results throughout the research process; the main causes of bias within focus groups come from the researcher or moderator and interpretation of the results (Sale, 2008; Smith, 2011). Processes were put in place and explained throughout this section to help eliminate these sources ensuring results are a true reflection of the situation explored and can be used with confidence. A debrief was used when the group had concluded in which the moderator and observer recorded initial assessments of the discussions, identifying any issues affecting analysis or interpretation of results and a summary and key points of discussions were produced for use in the analysis. Within the interpretation and analysis of the results various methods were used to ensure the verifiability of the results. The researcher transcribed the data ensuring familiarity with the data so that key themes could be identified. The analysis process was also consistently reviewed and discussed with the research team to limit researcher bias on the results (Lincoln and Guba, 1985).

Researchers need to recognise their background may influence the research process, if they have designed, collected, interpret and reported data they can exert bias on all stages. Reflexivity is the process of "self critical reflection on the research process and interpretation of data" (Gerish and Lacey, 2010, pg.136), the role of the researcher should be under as much scrutiny as the research itself (Carolan, 2003, pg.8). Reflexivity can be seen as a primary method of ensuring rigour, need transparency in description of how research was conducted and involves critical analysis of the researchers role (Alvesson and Skoldberg, 2000). The act of reflection enables the researcher to consider their own relationship with the research and how bias could have been exacerbated. Critical reflection and cautious

considerate approach to the research process can be seen to improve quality of the research therefore usefulness of findings (Finlay and Gough, 2003).

Within this process it is important to acknowledge the nurse-researcher role and the implications of this on all aspects of the research process. This is especially difficult when dealing with sensitive and controversial topics as participants often seek your opinions and ask for these during the interview process. It is essential in interpretation that these are not your thoughts but those voiced by the participants. Whilst during this project I was undertaking my research full time, this was not such an issue. To add to this I conducted my research in a different environment to that which I previously worked, it was still deemed important to consider.

One of the ways in which reflexivity is aided is to provide an audit or evidence trail. An evidence trail supports the data and has been documented throughout to show that the interpretation and analysis have been carried out rigorously and accurately, ensuring findings are credible and dependable (Parahoo, 2006). It is suggested there needs to be enough evidence from the study that claims made by the researcher are credible and supported (Finlay and Gough, 2003).

**Table 7 Critical reflection on Conducting Focus Groups - Strengths and Challenges**

Strengths	Challenges
<ul style="list-style-type: none"> <li>• My research was carried out in a different environment to where I previously worked; therefore I did not have to worry about preconceptions of my peers and existing relationships with work colleagues.</li> <li>• I was undertaking research as a full time research student therefore was not actively nursing so felt fully immersed in the research.</li> <li>• Observers present in the focus groups, assisted the debrief and summarising the focus groups main points. They also observed the moderator to ensure I was not asking leading questions or prompting answers.</li> </ul>	<ul style="list-style-type: none"> <li>• Having undertaken primary research for the first time and moderating a focus group, I found it difficult to not add in/contribute to discussion but instead sit back. Discussed this in Debriefs and advice given from the observer was to stick to interview guide and develop responses when pulled into discussion such as 'I would like to know your opinion on the subject'.</li> <li>• My background is in oncology and I have always had an interest in palliative care, which is why I chose to do this piece of research however not everyone has this interest.</li> <li>• Knowledge over the subject and trying not to prompt or coerce participants into certain responses.</li> </ul>

### 3.11 Summary

A total of three focus groups were conducted with a sample of nine ED nurses, four senior ED nurses, five HCA's, five PC nurses and the EOLC co-ordinator for the Trust. Overall an in-depth and detailed view has been gained regarding EOLC in the ED, which is felt could not have been obtained with any other method. This is due to the discussions surrounding interventions and these generating ideas that may not have been found in individual interviews, questionnaires or other qualitative methods. Key findings include barriers present, appropriateness of interventions and attitudes towards EOLC, illustrated in the next section.

## Main Findings

### 4.1 Introduction

Following thematic analysis of the focus groups set out in the previous chapter, codes were identified and themes developed, and by comparing each focus group several key themes emerged. The main themes were death within the ED, barriers to providing effective End of Life Care (EOLC), views on established interventions and suggested interventions to improve EOLC. The analysis process was undertaken rigorously and evidence provided on how the themes were reached.

**Table 8 - Summary of Main Themes**

Death in the ED	Experiences of EOLC in the ED	Negative experiences
		Getting patients out of the department
		Inappropriate admissions
	A Good Death (GD)	Pain free, comfort, support, time, addressing patient and family needs.
	EOLC is satisfying	Satisfying and rewarding Staff enjoyed this part Wanted to be there for patients Oncall team/area
Basic Function of the ED	Functioning ED, Fast pace, saving lives, quick fix, stabilise, trauma.	
Barriers to providing effective EOLC	Inappropriate Environment	Space
		Clinical Environment
		Resus Environment
	Lack of Information and Communication	Community Lack of Access to information
	Priority and Time	Lack of Time
Demand of Job Role		
Acutely sick vs. EOLC		
Views on Established Interventions	ABCD Assessment	+ve/-ve comments
	Rapid Two Stage Screening Tool (RTSST)	+ve/-ve comments
	SPEED Tool	+ve/-ve comments
	Palliative Care (PC) Champions	+ve comments
	PC referrals in the ED	Service provided, PC team
Suggested Interventions to Improve EOLC in the ED	Patient Pathway	Guide care, reference point to be used by any Healthcare Professional (HCP),_helps with senior support.
	Universal documentation	More information available, examples of documentation
	Education	Community
Managing expectations		

Initial findings in this study support the literature search that identifies a negative view of EOLC and barriers present in the ED as well as highlighting new findings. This study's focus was on interventions, the initial data demonstrated what is currently preventing optimal EOLC and can be used positively to influence intervention development. Further evidence from focus groups is in the appendices to support research findings (Appendix 17-22).

#### **4. 2 Death in the ED**

Participants were all able to give examples of EOLC, however most of these were negative mainly referring to what they consider inappropriate admissions at the EOL and that the ED is 'inappropriate' to provide EOLC (Appendix 17).

*"A patient brought in that was EOL, PC in a hospice... and they actually called an ambulance for her to be brought to hospital because they didn't know what was causing her to die even though it had already been discussed we just thought it was...not very nice or appropriate"*  
(ED RN FG2)

Participants' experience of good EOLC in the ED reflected the process of getting the patient to a more appropriate environment. No examples were provided of actual physical care given at the EOL; however one participant did acknowledge that EOLC received by patients was not always bad, utilising resources providing a peaceful death.

*"They were looked after in a cubicle...we dimmed the lights, we got mouth-care stuff for the family we did the best we could but...it still wasn't ideal but it was peaceful"* (ED RN FG1).

#### **A Good Death (GD)**

Throughout the groups there was recognition of what would constitute a GD, even though most of the experiences were negative, participants identified components involved in a GD and the importance of this. These were identified through definitions and when exploring negative experiences most participants analysed negatives, suggesting improvements to ensure a GD. Common components were; space, time, comfort and support not only of the patient in terms of being pain free but supporting the family, with death itself being peaceful and dignified.

#### **ED Professionals' attitudes to care**

It was evident in two groups that staff enjoyed this type of care, finding EOLC rewarding and satisfying. They wanted to ensure people died peacefully, supporting the family to make this time as easy as possible.

*“There is nothing more satisfying than to be able to give someone good palliative or EOLC...making the best you can for that person and their family” (ED Sister FG1).*

The staff wanted to be there for the patient and family, this was especially true if no relatives were present and they felt it was important that the patient was not alone. In contrast another group suggested an on-call team to take over the care of patients at the EOL; this involved a separate area with non-ED staff in line with the view that a GD meant getting them out of the department.

*“Someone to carry a bleep...they then go to that area and familiarise themselves with that patient and then they would be until that patient passed away.....their purpose would be to comfort the family, comfort the patient, make sure you’ve got the right analgesia and basically making EOL better” (ED RN FG3)*

One of the other participants in the group did question this approach suggesting whether more people involved in that patient care would be beneficial especially when you have spent time treating them. The response was still they would prefer the *“on-call”* team.

## **A Functioning ED**

This was brought up in all focus groups, demonstrating HCP attitude towards EOLC and what they see as the primary function of the ED. The primary function was seen throughout as a place for people requiring *“life-saving”* treatment, a fast paced area where they stabilise patients, transferring them to another area after this period of acute illness – not the provision of holistic EOLC.

*“They [patients at the EOL] don’t need to be in A&E it is not an accident or an emergency” (ED RN FG2)*

*“We do the quick-fix, doesn’t matter about the long-term implications, just fix or break them that’s it because we stabilise and ship them out...that’s what we do” (ED CN FG2).*

It was also referred to and that care is focussed on *“life-saving”* with participants feeling that a lot of their education is based on this idea and doctors in particular were acknowledged to have an attitude focussing on *“saving lives”*.

## **4.3 Barriers to Effective End of Life Care in the ED – Environment**

Participants identified the environment as a major obstacle to the provision of EOLC in the ED, making very bold statements about the appropriateness of the environment to provide EOLC with some relating it back to personal experiences (Appendix 18).

*“To me it’s not the right environment I’ve got personal experience of being with a relative that is dying...its horrible” (ED Sister FG1).*

These views were further justified by participants viewing the ED as a ‘*clinical environment*’ when people’s choice to die at home was influenced by the fact they are in comfortable and familiar surroundings. One group gave the example on labour wards providing a comfortable space for bereaved parents, whilst in the other groups the ward was referred to as an environment more conducive with optimal EOLC.

*“I think in a hospital it’s clinical isn’t it? That’s why people opt to be at home it’s their own surroundings it’s their stuff” (ED RN FG3).*

Lack of space and privacy in the ED was also seen to hinder EOLC with participants acknowledging that the environment does not allow HCP to provide some of the basic components associated with EOLC.

*“We can’t do one-to-one nursing...we can’t provide the comfort to the patient or even their family...we don’t have you know a Chaplin, we don’t even have cups to do a proper cup of tea or provide them with food in the middle of the night or overnight stays or there is no way in an A&E department we can accommodate that” (ED RN FG2).*

The resuscitation department (resus) received a lot of attention, with the majority of participants agreeing that it is not an appropriate place for people to receive EOLC, commenting they would not want that for their loved ones. There were several factors identified that contributed to this view; one was the noise associated with the area due to trauma alerts, machines and the general resuscitation of critically-ill patients. Participants did not think this was conducive to ideal EOLC which should be given in a peaceful and quiet environment.

*“It’s a horrible environment in the resus room. It is so loud there is always a trauma alert going on, there is always shouting, it is very difficult to give someone a dignified and peaceful time with their family...and that’s the last thing they are going to remember” (ED Sister FG1).*

It was not only the patients that were considered but how the environment affected the family and relatives. There is a room that is attached to the resus department where relatives are taken whilst patients are being treated, most participants referred to this as the “quiet room”. Whilst referred to as the “quiet room” most participants felt it was still noisy and everything going on within the department could be heard which does not aid the grieving process.

#### 4.4 Barriers - Lack of Information and Communication

When exploring barriers affecting EOLC in the ED, lack of information and communication were frequently discussed; firstly, participants examined the lack of information and documentation in the community, frequently commenting on the validity of documentation (Appendix 19). They maintained that patients' wishes were not upheld even when documented and in some cases there was confusion over the validity of the Do Not Attempt Resuscitate (DNAR) in the community. All of these factors were felt to lead to inappropriate admissions and ultimately patients' wishes not being upheld.

Participants experienced patients who were admitted to the ED when previously they had stated they did not want to be hospitalised at the EOL. Participants found this difficult as the patient's wishes were not being upheld at this difficult time, often occurring as a result of documentation being lost or not filled in appropriately.

*"It wasn't appropriate when she had specifically requested when she was awake and completely able that she did not want to die in hospital" (ED RN FG2).*

The validity of the DNAR documentation was discussed as patients are brought to the department in a peri-arrest state with a DNAR in place as people are not aware of the validity of the document which sometimes has led to inappropriate resuscitation later establish this was against patient wishes.

*"Usually the crews divert because they are not aware of the validity of the community DNAR...They are in a hard place as if they carry on they could be fired or lose their registration for not acting appropriately so they will bring the patient here rather than letting patients die in the back of the truck" (ED CN FG2).*

It was from this that many participants advocated the use of universal document that would provide information in a variety of settings with all decisions including a DNAR being respected and upheld, transferable to different healthcare settings. Secondly participants spoke about the lack of access to information on admission to the ED, stating it was difficult to get information unless they come in with the information.

*"The problem we have is we have four hours to find out everything we can about that person and....we rely a lot on what has been gathered by the ambulance before...information the doctor knows...or relatives have imparted information that they forget to tell you" (ED CN FG2).*

One nurse referred to it becoming at some points a “*detective game*” trying to find all the bits of information from the patient. This is not a barrier specifically associated with EOLC but in relation to EOLC it can be difficult with no previous history you have “*start from scratch*” and participants found they then had to manage the expectations of the relatives if a very pro-active approach was taken.

*“So you might get patients who come in and we start doing loads of tests...because we don’t know that they’re actually dying...the relatives hopes are actually built-up because we’re being pro-active in our treatment and we have to tell them the same thing again and upset them” (EOL Co-ordinator FG3).*

#### **4.5 Barriers - Assessing Priority, Demands and Lack of Time**

Priority and time were addressed as major barriers to the provision of EOLC in the ED; there was a documented lack of time to be able to spend with patients at the EOL (Appendix 20). The participants acknowledged that the lack of time was due to different demands present within the ED. One of which was patients requiring varying degrees of attention with participants wanting to give everyone the appropriate time and care.

*“We are so limited in what we can actually do...I know it’s really important but everyone is really important and we are always continuously overloaded here and unfortunately these people don’t get anymore care than the next and you’re having to spread yourself out so thinly so it’s very difficult to actually make differences to the care you’re giving” (ED Sister FG3).*

A specific example of demands in the ED was the presence of acutely sick patients as well as those at the EOL and ED providers having to assess which patient takes priority.

*“It’s very difficult you have someone who is about to die and that someone who has just come in dreadful pain and really poorly...where do you go?” (ED RN FG1)*

Some examined the situation very pragmatically assessing that nothing more could be done for patients at the EOL apart from making them comfortable yet the acutely sick patient coming in could be resuscitated requiring their immediate attention.

*“To a certain degree you think I can’t do anymore for you because you are passed that point you have to kind of...it sounds horrible but prioritise...” (ED RN FG3)*

Other pressures discussed were bed availability, limited staffing and one group considered the extending role of the nurse as an additional pressure causing staff to constantly re-

evaluate where they are needed. Participants felt that it was due to all these factors that EOLC is currently neglected, as priorities lie elsewhere within the ED.

*“If you’re in resus and there’s only three nurses plus two trauma alerts coming in even with all the will in the world you physically can’t give them all the time and attention they should get when they are palliative which they should” (ED RN FG2)*

Overall the participants acknowledged that due to demands present in the ED such as the large amount of patients, the acutely sick, bed pressures and staffing EOLC becomes difficult and there is limited time for them to provide EOLC. One participant made a very poignant statement that it often feels like *“processing people and not nursing”*.

#### **4.6 Views on Established Interventions**

The established interventions were discussed but only the ABCD tool received positive feedback, the other tools were seen to have major flaws in terms of use in the ED. Education and documentation were mentioned within all the groups however not in relation to the established interventions.

##### **ABCD Assessment Tool**

The ABCD tool (Diagram 3) focuses on immediate priorities of someone at the EOL encompassing advance directives (AD), symptom control, caregivers at the bedside and whether the patient has decision-making capacity. The majority preferred the ABCD assessment; this was due to it being *‘quick, clear and concise’* participants felt it reflected *‘how they worked’* (Appendix 21).

*“It’s clear, its normal to what we do, except for when you have a palliative patient you apply it slightly differently, just a very quick assessment tool and it makes you think a little bit more...when you are doing your initial assessment what further steps you could take, so if I was using that I think I would think about things a little bit more”(ED RN FG2)*

Participants suggested combining with the Rapid Two Stage Screening Tool making a flowchart for PC patients coming into the ED, others noted that caution needs to be applied as could become a *‘tick-box exercise’*. There were negative views due to its similarity to the original ABCD assessment, those who had this opinion suggested changing the lettering but keeping the idea of focusing on patient priorities. There was only one participant, who expressed a severely negative opinion;

*“I didn’t like looking at just that ABCD... we are so used to a very different ABCD...it is nothing like what we know and I instantly disliked that straight away just because of the lettering” (ED RN FG1)*

### **Rapid Two Stage Screening Tool (RTSST)**

The RTSST (Diagram 2) aims to identify unmet PC in the ED alongside placing a social worker and PC champions in the ED. Overall this tool was viewed negatively, participants commented on the age limit, stating that everyone should have access to PC regardless of age (Appendix 20). Within another group it was the specification of a life-limiting condition which they felt would entail a huge patient group, too large for a PC team and they would be constantly in the department and *“never off the phone”*(FG3).

### **SPEED Tool**

This tool (Table 5) was set up to provide a comprehensive assessment of oncology patient’s PC needs on admission to the ED. The SPEED tool participants felt looked in *‘too much depth’* at the patient, being more suited for ward based care whilst others saw the SPEED tool as useful providing a means to communicate with patient in a *‘checklist approach’* of how they can make that patient more comfortable (Appendix 21).

*“The SPEED tool could be quite useful, when you think how much people can communicate, these are things we can change very quickly” (ED RN FG3)*

*“And I think sometimes if we look in too much depth...we are kind of turning into a ward in some sense we want to get away from looking deep into it and keeping them longer we want to get them into another place quicker” (ED RN FG2)*

Both the SPEED tool and RTSST were very successful when piloted in the US, yet within this study received mainly negative feedback which could be attributed to the noticeable differences in healthcare systems and resources.

### **Palliative Care Champions**

Overall there was confusion within the groups whether PC champions were already present within the ED; however participants liked the idea of having a designated PC nurse whom they could gain advice from. Within one of the groups this was not discussed, however the other two focus groups discussed the benefits and more education surrounding these roles would be beneficial (Appendix 21).

*“We have nurses for most things in the ED...so it wouldn't be a bad idea if we had someone to communicate to for advice because it's very hard to take on board everything that's actually happening in the department” (ED Sister FG3)*

### **Palliative Care referrals within ED**

Within all of the background interventions there was a heavy emphasis on referral to PC services which was discussed in all three groups, whether there were PC services available and if they could make referrals. PC nurses noted that they do not get many referrals from the department which they put down to numerous reasons; lack of knowledge about the service, time limits placed on the department and lack of information regarding the palliative diagnosis on admission. If participants did not know about the PC team they liken the ideal service to the oncology service available within the trust, other participants saw the team as being a point of reference or giving advice. PC saw their role in the ED, as providing advice acting as a point of reference for HCP in the department.

*“Someone we can call for help to say we've got this person...we can't get them back, they are in the ED or we are having problems what would you suggest” (ED RN FG1)*

### **4.7 Suggested Interventions to Improve End of Life Care in the ED**

Many participants had their own ideas and suggestions as to interventions that could be used within the ED to improve EOLC (Appendix 22). These ideas were based upon discussions in the focus groups and have stemmed from identifying barriers and how these can be overcome.

#### **Patient Pathway**

A popular idea was a pathway for patients entering the ED at the EOL; some participants saw this as a guide to get patients out of the department while others described it as optimising care and acting as a point of reference to guide PC.

*“It's quick and easy for anybody to use...a quick reference, it gives you all the information...if it's quick and easy to follow you will find that people will be using and implementing it a lot more because it's going to be time worthy...it's simple so anyone can use it juniors, HCAs, students” (ED RN FG2)*

The fractured Neck of Femur pathway was given as an example of a pathway used in the ED which it could be loosely based upon. Participants considered priorities to be included on the pathway as analgesia assessment, communication and comfort. By having a pathway as

a guide, participants felt staff would have increased confidence providing this type of care and making decisions not reliant on senior help. Nurses also saw this as being helpful for the medical staff, recognising they are sometimes frightened to make decisions surrounding EOLC.

*“If we’ve got something more like this that the juniors can sort of look more... they’re not scared to make that decisions they are then following...a protocol or guide...this is what you can do” (ED RN FG2).*

Within one of the groups the mention of a designated pathway sparked up controversial debates and opinions surrounding the LCP, two participants thought this pathway was inappropriately used whereas others had seen the pathway used to provide excellent EOLC. The overall feeling was a pathway should not take away any treatment, but essential it was interpreted correctly highlighting that education is vital.

## **Documentation**

Improvements in documentation were discussed throughout; with the main requirement being to have information readily available on admission so care provided is in line with patient wishes and goals of care – a universal document.

*“We need to make sure that everything is either clearly documented or the patient comes in with something suitable to be able to inform us of the patient condition” (ED RN FG3)*

Participants suggested that if paperwork was used needed to make sure *“it isn’t just paper”* but treated as an important document in the community and hospitals. There were numerous examples of documentation used in other areas of healthcare; passport to health, sickle cell cards and alert bracelets that participants felt could enhance care as information is readily available. The general consensus was that patients should have a universal document that is valid in all settings, conveying their wishes.

*“The sickle cell patients come in with the information what painkillers they like, what they don’t like...it’s very specific and having something like that for PC would be really good” (ED RN FG1).*

However as noted by PC nurses, patients at the EOL often change their mind and their condition can change rapidly so at what point could you update their choices? Compliance was addressed with these interventions being dependant on how well the documentation

was completed and if people carried it with them. Others suggested documentation in terms of care-plans specific to EOLC including priorities of what they could do for the patient.

*“No current documentation for EOLC, unless you have a specific performa for EOLC, like you would for specific other care plans...so a list of things what we can do for the patient” (ED RN FG3)*

One participant questioned whether the introduction of more paperwork would improve the care given, maintaining the current “care rounds” in place were applicable and should be utilised in EOLC instead of more documentation.

*“Would introducing new documentation change what we do? Would we give more care? I don’t think we need more paperwork” (ED Sister FG3).*

### **Trigger system**

A Trigger system was suggested showing palliative status of patient on admission; therefore appropriate treatment could be given. This admission would also trigger contact in the community potentially assisting getting patients back into the community. PC nurses were in agreement suggesting it could be used to alert them and whether it was appropriate for them to review patient.

*“I think having an online system...that triggers straight away as soon as that person comes into hospital you know they are palliative...this and this are already in place and you’re not having to wait for someone else to tell you”(ED RN FG2).*

### **Education**

Whilst education was part of the established interventions; symptom control, communication and PC training were not discussed. Instead education was thought to be needed in the community and the ED surrounding resources and services available. Within the community, participants felt education was needed for patients and family regarding conditions and expectations at the EOL. Addressing this area may stop inappropriate admissions, with families less inclined to call emergency services when patients deteriorated. In one group they also suggested education for the ambulance crew in managing the patient ensuring admission to hospital was in line with their wishes.

*“In the community the relatives then get worried because I didn’t expect this to oh my god let’s call an ambulance because this isn’t meant to happen. I think in the community maybe some....not saying every situation...the family haven’t been as educated or understand what*

*is going to happen, then they panic bring the relatives to hospital and again we are stuck in that cycle” (ED Sister FG2).*

Other participants considered the awareness of resources available to patients in the community and that if people were more aware of what was available they may not come into hospital.

*“It might be the case they are thinking the only way we’re going to get the appropriate pain management or treatment in hospital because a lot of people don’t realise how much can be put into the community” (ED RN FG1)*

Participants recognised the difficulties surrounding this and that education has limitations. PC nurses raised this point that no matter how much support and education is in place, there are some admissions that will not be avoided due to hospitals being seen as a “safe place” where relatives can take their loved ones for support and comfort.

*“No matter how many times you’ve told someone unless they’ve already experienced it once they never expect it just from personal experience of telling my relatives exactly what’s going to happen and when it actually came to it they...weren’t expecting it” (ED RN FG2).*

Within the ED participants suggested education would be useful surrounding services and resources available to them ensuring people knew who to contact not relying on senior support.

*“Just so actually everyone knows what’s going on...so they know what people to ring in a certain situation, so they’re not stuck and then having to go to a senior” (HCA FG3)*

There was an acknowledgement by participants that they encounter many different conditions it is difficult to know everything. Focusing mainly on oncology patients at the EOL, they considered other patient groups and their own lack of knowledge on resources and services available for other patient groups.

*“But you’ve also got patients at the EOL COPD haven’t you we’re all focussing on cancers really. A COPD patient that was at the EOL I wouldn’t even know who to go to for that, I wouldn’t have any ideas...I wouldn’t know who to contact” (ED RN FG2)*

## 4.8 'Post-It Interventions'

Table 9 - 'Post-It Interventions'

Focus Group 1	Focus Groups 2	Focus Group 3
<ol style="list-style-type: none"><li>1. Pathway (5 Participants)</li><li>2. Universal documentation (3)</li><li>3. Link with PC team (2)</li><li>4. Symptom/pain management (2)</li><li>5. Relatives room (1)</li><li>6. Dignity in care (1)</li></ol>	<ol style="list-style-type: none"><li>1. Universal documentation (5 participants)</li><li>2. Pathway (5)</li><li>3. Trigger system (4)</li><li>4. Education (3)</li><li>5. Pain management tool (2)</li><li>6. PC team support (1)</li></ol>	<ol style="list-style-type: none"><li>1. Improved environment (4 participants )</li><li>2. Education and Training for staff (1)</li><li>3. Pain free (2)</li><li>4. More time (1)</li><li>5. More staff (1)</li></ol>

Table 9 shows the exercise used to conclude the groups where participants suggested interventions that could improve EOLC in the ED. Whilst it demonstrates the main themes it also highlighted the dynamics and understanding of the topics covered. The first two groups were fully immersed in the discussion and wanted to improve the situation generating numerous ideas, giving knowledgeable and in some cases expert opinions on the topics. The third focus group seemed very hesitant to change and the group discussions focussed on what was wrong and reflected in their answers and not directly how the situation could be improved.

## 4.9 Critical Reflection on Data Analysis and Findings

At all points during qualitative data the researchers' role and influence over the data set should be scrutinised to ensure credibility in the results and as a result usefulness in findings. During data analysis many processes were put in place to ensure that interpretation present an accurate account of the findings, Gerish and Lacey (2010) suggest that readers can judge authenticity of findings and interpretation by including interview data in findings. Other processes have been laid out throughout the section such as frameworks for analysis and discussions with the research team (Table 9).

**Table 10 - Critical Reflection of Data Analysis and Findings**

Strengths	Challenges
<ul style="list-style-type: none"> <li>• Frameworks used for data analysis provided structure and process.</li> <li>• Thematic network analysis provided a means to present how the themes were conceived.</li> <li>• Each stage was discussed with the research team to ensure results were replicable.</li> </ul>	<ul style="list-style-type: none"> <li>• The amount of data from the three focus groups was initially overwhelming.</li> <li>• The time it took to read and familiarise myself with the data set and pre-conceived themes start to emerge. These were discussed with the research team before codes and themes were developed.</li> <li>• By analysing the data set myself, it became subjective to how I interpreted what participants said. Addressed by having data from the focus groups within the text.</li> </ul>

#### **4.10 Summary**

The main findings from the groups have been outlined with all the quotes within the themes being presented in the appendices 17-22. The participants gave a valuable and unique insight into the barriers the ED presents in reference to EOLC, examining how this situation can be improved. The next section will dissect the main findings providing recommendations on how this research can be used to assist in the improvement of EOLC in the ED.

## Discussion

### 5.1 Introduction

The main themes identified after analysing the data were the preconceptions of death in the ED, perceived barriers present in the ED and discussions surrounding interventions. Within this section the two overarching themes; interventions and culture within the ED, will be explored using previous research to explore further the findings. The implications of the study will be discussed alongside the limitations and suggestions for further research.

### 5.2 Challenges around Interventions

The established interventions overall were seen as unworkable and unrealistic. There was positivity towards the ABCD assessment (Diagram 3) due to ease of use, rapid assessment reflecting the EDs approach to care. This overall shows participants desire for an algorithmic tool that is simple, clear showing processes of what they can do for the patient. As a practical tool it is in line with current policies on EOLC identifying care components required for a GD (DoH, 2008). Possible interventions to improve EOLC have been less well researched, within this study whilst discussion took place around established interventions; barriers were identified and from this provided a basis for participants' suggested interventions. The focus group method assisted this approach as participants discussed barriers this naturally led onto how they could overcome these barriers, with the hope they can be addressed this may assist in the delivery of EOLC.

Participants put forward interventions that they saw as being useful to aid EOLC in the ED, the most popular being a 'pathway'. This was seen as a way to get patients out of the ED due to perception it was an inappropriate place to provide EOLC. Others suggested a 'pathway' that optimised care in the ED; identifying priorities for the patient similar to the ABCD assessment of which '*pain and comfort*' would be essential. The RCP (2012) and EOLC Strategy (2008) both advocate the use of a pathway. Patterson et al.,(2009) applied the modified LCP to the ED to introduce consistency to care, improving the experience for dying patients. The study showed a more structured and confident approach to care with improved documentation. It needs to be recognised that the pathway was applied to all patients within the last 24 hours of life and was not condition specific, however components of the modified LCP could be utilised to provide a more structured approach to the way EOLC is delivered in the ED. Some caution should be applied when using the word 'pathway' due to the controversy surrounding the LCP – however this was the term participants used so it has been used within the text. The DoH (2013) advocates the use of EOL care-plans as the alternate terminology. Participants identified education was essential

surrounding any interventions or pathway implemented in the ED alongside this the DoH (2008) suggests education is critical to improving EOLC.

It should be acknowledged that the supportive care pathway (SCP) was developed within the trust where research took place and is used in hospitals around the West Midlands. When the study took place it was widely used throughout the trust, but not in the ED. This document is no longer in use in trust, initially set out like the 'universal' document the participants felt was needed, to be applied across settings, recent research shows its application in reality was similar to the LCP.

Participants wanted to '*be there*' for patients identifying time as a major barrier to providing quality EOLC. Not only this but participants felt there were other competing demands; mainly coming from the acutely sick who in their opinion required just as much care as those at the EOL. In conjunction, Smith et al.(2009) acknowledges patients with PC needs were sometimes considered a lower priority than other patients within the department. Bailey et al., (2011a) highlighted this where the 'subtacular' patient often associated with terminal-illness is considered a lower priority and their PC needs are often neglected due to those requiring rapid stabilisation; the 'spectacular' patient. Participants acknowledged that 'patients only had four hours in the ED' which could be them referring to the pressure on them to decrease waiting times and achieve waiting time targets. In most other studies that considered the lack of time this was the main focus, requirement and pressure to decrease hence stay within the ED (Clarke, 2008; Beckstrand et al.,2012a; Richards et, al 2011; Glajchen, 2011). It is important to overcome the perception EOLC takes hours by putting in place basic checks or interventions that would allow HCP to be there, offer support and comfort without compromising other patients' care or adding additional pressures. This could be considered alongside or in conjunction with the suggested patient pathway. Previous studies (Redley et al.,2003; Rich, 2005) report that families consistently identified certain needs when accompanying a relative to the ED, this could be combined in a tool or checklist to aid staff in addressing the needs of patients and relatives at the EOL, reducing the burden of their workload and improving the experience.

The lack of information and communication available in the ED is not specific to EOLC but in the provision of all care. Smith et al.'s (2009) study is consistent with this study's findings; it was the primary obstacle ED providers found when trying to provide care appropriate to patients' wishes. Comparable to participants within this study there was a lack of information from primary care providers which needs to be addressed to ensure patients' wishes are being upheld. Not only did participants think there was a lack of information from the community but also the lack of access to information on admission made it difficult to assess

appropriate goals of care and plan appropriate treatment. This can be detrimental in EOLC as it is unknown to what extent patients are aware of diagnosis, existing wishes in regard to treatment or DNAR (Foreno et al.,2012). Other studies also looked at the ED staff having to have difficult conversations with the family, which they felt was not appropriate upon meeting relatives for the first time although not addressed by participants (Smith et al.,2009; Norton et al.,2011). Whilst this has been explored in the US, within the UK there has been very little acknowledgment of this problem, this study illustrates that lack of information is a barrier in the provision of EOLC delivery in the ED.

The use of Advance Directives (AD) and Advance Care Planning (ACP) in the US has been seen to provide a framework for ED providers in clinical and ethical care of patients at the EOL (Clarke, 2008). However, these can still be too generalised and there is difficulty translating them to specific treatment plans consistent with the patient's wishes which can be further complicated by distressed relatives unaware of AD (Clarke, 2008; Smith et al.,2009; Forero et al.,2012). Chan (2004) suggests there is a need to provide further education around addressing patient's goals at the EOL and initiating ACP. The National Gold Standard Framework (GSF) suggest that ACP and Advance Decisions Refusing Treatment (ADRT) are a key part of quality provision at the EOL and has been found to ensure patient focussed care. It is included in the EOLC Strategy (2008) as has been shown to improve the provision of services and increasing realistic hopes, empowering patients (GSF, 2012). Despite this evidence of how ACP and AD improve care they are not being utilised in some areas of healthcare in the UK. Whilst used extensively in some settings within the ED staff are not aware of such tools as The Preferred Priorities of care Tool (End of Life Care Strategy, 2008). Neither are there systems in place in the UK offering interventions that address goals of care at the EOL within the ED.

Findings revealed participants wanted a universal document to overcome this barrier that upholds patient's wishes in each healthcare setting where AD and ACP could be utilised. Additionally this could provide consistency of care across healthcare settings, making it easier for HCP to access information. The development of this document is an area which is essential in future research combining HCP's views to ensure it is appropriate and upheld in both acute and primary care settings.

The Royal College of Physicians (RCP) report on 'Cancer Patients in Crisis' (2012) identifies lack of access to information on admission to acute units as an obstacle in the provision of care especially at the EOL. Findings showed that HCP in the ED were heavily reliant on patients and carers for information which is consistent with this study's findings. Patients and relatives that were questioned after accessing the ED commented on the poor

communication and lack of information available (RCP, 2012). The proposal put forward in the RCP is promoting a clear management plan available at all times that explains treatment, diagnosis, important decisions. This will provide HCP with a summary of individual patient's cancer journey at all times informing their decision-making on admission to ED and be available in the community. The RCP proposes emergency contingency plans, identifying patient preferences at the EOL utilising AD and ACP. The RCP (2012) recognises limitations that it is dependent upon the patient's compliance but also HCP recognition of conditions and awareness of documentation. It is tailored towards those with an oncological diagnosis but could be adapted for the purpose of providing a document which contains diagnosis, treatment preferences and any AD for all of those patients with life-limiting illnesses.

Participants focussed on the lack of space and privacy as well as the environment not being conducive to providing EOLC. The environment is widely documented in previous literature to be a barrier in providing EOLC in the ED mainly focussing on the physical layout of the ED (Beckstrand et al., 2012a; Smith et al., 2009; Clarke et al., 2008; Glajchen et al., 2011). Whilst some aspects of the environment can be immediately improved in terms of utilising resources to accommodate EOLC, physically changing the environment is not feasible but something that should be considered in the future.

Education has been covered in previous literature and policies (DoH, 2008) stating that it is essential in order to improve EOLC. Within other studies the priority of education has been placed on physical care and communication (Smith et al., 2009; Beckstrand et al., 2012a; Clarke, 2008). This study has identified that ED staff feel there should be increased education in the community surrounding expectations at the EOL in addition to what services are available in the community which may prevent admissions to the ED. These findings offer an important insight into areas previously not covered or included in policy recommendations (DH 2008; RCP, 2012); it is essential for all healthcare staff to have knowledge surrounding care for the dying and this is critical in improving EOLC. Furthermore EOLC needs to be mandatory in training at all levels and staff groups (DoH, 2008). Education will assist to improve HCP awareness surrounding the provision of EOLC in the ED, first the culture embedded in the ED needs to be addressed.

### **5.3 End of Life Care – Not in the ED**

The findings suggest a deeper barrier to EOLC provision - the organisational culture present in the ED and the perception that EOLC does not belong in this setting. It is an emergency centred environment where EOLC does not take priority instead that of patients with injuries or illnesses which require immediate stabilisation; the 'spectacular' patient' (Bailey et al., 2011b). Keywords used throughout groups demonstrate this point that the ED was referred

to as a place for *'life-saving'*, *'quick-fix'*, *'mending or breaking patients'* and stabilisation of patients. Not all of these terms fit with the theoretical concept of EOLC which is centred on the individual patient (Quest et al., 2011).

The concept of organisational culture is multi-layered and complex, there is not a set definition of what 'culture' is and therefore of what 'organisational culture' is. Schein (2004) summaries organisational culture as a complex mixture of different elements that influence the way things are done, understood, judged and valued involving attitudes, values, beliefs and norms of behaviour. Over the past two decades interest in this concept has grown, especially in the UK in the light of recent 'scandals' in healthcare (Davies et al., 2000). This has led to emphasis on exploring and promoting beliefs, values, and norms of behaviour in practice that support delivery of high quality professional practice based on and around needs of patients and carers (Konteh et, al. 2010).

However some cultures can be recognised as a closed system that do not adequately address and account for customers and service users. Kemp and Davies (2006) suggest identifying cultural deficiencies and gaps is essential in advocating and introducing a new culture. For cultural development to be successful, current reality of culture must e acknowledged as well as structural reorganisation and system reform (Kemp and Davies, 2006). This study can provide the current organisational culture in the ED so efforts can be made to address this before any structural or system changes are made (McQueen, 2004).

There appeared to be a focus on transferring patients at the EOL out of the department, as care provided in other areas was seen as more conducive with ideal EOLC. There seemed to be a basic issue with the feasibility of providing EOLC in this environment where staff used barriers as a coping mechanism and justification to why it is not a suitable environment. They appeared to avoid issues pertaining to palliative and dying patients demonstrating a lack of emotional intelligence and often referring back to the primary purpose and function of the ED. They appeared to avoid issues pertaining to palliative and dying patients demonstrating a lack of emotional intelligence and often referring back to the primary purpose and function of the ED. Emotional Intelligence, a concept recognised in social psychology and in recent times in healthcare specifically nursing where it is important to understand patient perspectives. Simplistically it can be viewed as "the ability to manage your own emotions while interpreting other people's" (Evans and Allen, 2002, pg.41). Goleman (2001) identifies essential components that encompasses emotional intelligence; self awareness, self management, social awareness and relationship management. Previous literature supports that emotional intelligent individuals can recognise and regulate their own emotions as well as recognise others emotional states using intuition to guide them

(Goleman and Cherniss, 2001; McQueen, 2004; Bailey et al., 2011). In relation to nursing and especially within the ED, nurses ability to manage emotions and understand emotions of their patients and relatives is an asset in providing care, assisting in accommodate patient goals and overcome adversity in their practice (Evans and Allen, 2002).

By participants avoiding issues pertaining to palliative issues and referring the ED as a “life-saving environment” and an inappropriate environment for EOLC to take place they are not ‘investing in the therapeutic relationship’ that leads to the development of emotional intelligence which can benefit nurses and patients in relation to the care they may receive in the ED (Bailey et al., 2011). Alternatively if we examine further the primary purpose and nature of the ED this is changing due to the ageing population and current disease trajectories (Kenen, 2010; Bailey et al. 2011b). The service needs to find a way to adapt to include this patient group coming into the ED at the EOL and receiving the appropriate care.

This culture was evident in the examination of the established interventions where the SPEED tool was deemed too lengthy yet it identifies what many would consider important elements involved in EOLC and a GD. It looked at the patient *‘in too much depth’* which was ascertained as not required within the ED but the need to know the basics in order to stabilise the patient and move them. EOLC was seen as preferable in a ward based environment whilst many would concede this is true it is evident that EOLC is becoming part of the ED and needs to be considered as part of the everyday function of the ED. Staff seem reluctant to acknowledge EOLC as part of ED yet all could give examples of EOLC given in this environment, the fact that these were all negative reveals a need to improve and acknowledge EOLC is given in this setting.

Within the EOLC strategy (DoH, 2008) one of the main focuses is preferred place of care, emphasising the increasing amount of people who wish to die at home or in hospices. Due to the complex dying process and unpredictability of terminal-illnesses this sometimes cannot be achieved. Currently fifty-four percent of people die in hospital (National EOLC Intelligence Network, 2011) and ninety-percent of people have an admission to hospital in the last year of life (Gomes and Higgson, 2008; Office For National Statistics, 2008), these statistics show an urgent need to improve the level of EOLC given in the ED. In turn whilst policy continues to drive care into the community (DoH, 2008; Cancer Reform Strategy, 2007) there are some admissions that remain unavoidable as people are scared and distressed at the EOL and will seek out comfort in the form of an ED admission where expert care is provided immediately. Additionally there is uncertainty surrounding prognosis at the EOL, so admission to ED could surround this as well as fear and anxiety (Gott et, al. 2013).

The organisational culture that is deeply embedded in the ED and there is an immediate need to counteract the perception that EOLC does not belong in this setting. Services need to reflect their service users and Kemp and Davies (2006) suggest that patients and carers should be allies in the continuing development to improve the 'culture' and service. Whilst culture needs to be addressed this also needs to run alongside structural changes not only in this environment but the wider system. The interventions should be tailored to '*how the ED works*', requiring them to be quick, concise, showing clear patient priorities. This study adds is there is a requirement for interventions to be multi-faceted not only addressing barriers but going beyond the surface to encompass and neutralise culture. It is suggested that education is essential in conjunction with this, ensuring all staff have a basic level of knowledge and skill to provide good EOLC as well as illustrating that ED providers are uniquely placed to provide excellent palliative and EOLC. Whilst it does need to be acknowledged that EOLC requires a different skill set these can still be utilised in order to provide the GD participants recognised. ED providers are the first people patients and relatives come into contact with to provide; comfort, support, pain and symptom relief – all of which are aspects that contribute to a GD. ED providers are uniquely positioned at the gateway into the hospital to start the process and initiate the foundation for good EOLC and the provision of a GD.

**Table 10 – What is already known and What has this Study Added?**

<b>What is already known</b>	<b>What this Study adds?</b>
<p><b>Barriers preventing good EOLC</b> Attitudinal barriers and structural barriers were identified in the literature review that effected EOLC.</p>	<p><b>Barriers</b> The participants in the study found the same barriers; inappropriate environment, lack of information and communication, Priority and Lack of time.</p>
<p><b>Improvements in communication and documentation</b> Inadequate documentation was often identified as a barrier to prevent good EOLC. All articles suggested a need to improve documentation and communication between primary care providers and the ED.</p>	<p><b>Interventions</b> Participant’s feedback on the interventions provides an insight into what will/won’t work in the ED. Any intervention needs to be ‘clear, concise and almost follow a pathway or algorithm’. The feedback was mostly negative to all the interventions found in the literature however other ideas were discussed in relation to what would work and what wouldn’t work.</p>
<p><b>Further education and training</b> Increased Training and Education especially surrounding the ability to discuss care at the EOL. HCP in various study’s felt they had insufficient knowledge in regard to pain management and training in pain management that was essential to improve EOLC.</p>	<p><b>Universal Documentation</b> This study advocates the use of an universal document, development of a tool which addresses the needs of terminally ill patients accessing the ED.</p>
<p><b>Interventions</b> Within the study, interventions were identified that were being used to improve EOLC.</p>	<p><b>EOLC – not in the ED</b> An organisational culture present and the perception that EOLC does not belong in the ED. From this we can establish that any tool needs to address this culture and tailored to ‘how the ED works’.</p>

#### **5.4 Limitations**

At the time the study was conducted a new scheme was being launched, its aim was to improve EOLC through training bereavement link nurses more intensively to educate staff. Whilst not thought to affect results, if study was repeated different results might be obtained due to education and training received. However the findings from this study are thought to be of use to the scheme as similar barriers are likely to be experienced. Within the Midlands, at the time the study was undertaken, community services were undergoing changes to services that may account for lack of clarity surrounding what was available in the community.

Time has to be acknowledged as a constraint to this study as ideally more focus groups would have carried out however due to clinical demand in the department and completion time for the project was limited this could not realistically be achieved. Further to this there

was not the time to pilot the handouts as thoroughly as initially intended. Although tested in the pilot group and through various other HCP not involved directly with study. Additionally the focus group could of allowed for more time for the participants to review the proposed interventions, Whilst this was acknowledged in the first focus group and further explanation was given other groups, it was still not clear if participants fully understood interventions which could have affected responses to proposed interventions.

Creswell (2007) suggests with any qualitative research there is room for bias through the researcher, sample and analysis however methods have been put in place throughout this study to ensure each bias is minimised, ensuring trustworthiness of data. Observers were present limiting the researcher bias and that the moderator did not have an overriding effect on the focus groups. A debrief was used after each focus group to confirm that key points obtained were true to the group's discussions and themes presented reflected discussion, ensuring credibility of results. The analysis and main findings were discussed and clarified with the research team ensuring findings were representative of the focus groups, increasing validity of the data. An evidence trail has been provided through the chapters demonstrating the development of focus groups, analysis of data and how themes and conclusions were reached to increase confidence on the rigour to which the study has been conducted and ensure it is an accurate representation of findings.

Initially the study set out to have a range of HCP attend the focus group this included nurses, doctors and HCA's. However due to ED workload demands on the allocated days of the focus groups this was not possible. This can be seen to limit the findings however in turn it provides another research opportunity to include medical views and opinions on EOLC in the ED alongside other HCP views. The generalisation of the research is limited as it only reflects views from one hospital however the major themes within the study are consistent with previous research within this area. This is thought to add to the study's transferability however this is new research within the UK providing an insight and evidence upon which future research can be built.

## **5.5 Implications for Practice and Policy**

Limited research has been conducted in UK EDs about ED provider's views of EOLC (Paterson et al., 2009), the recommendations from this study come from front line staff, who provide the care and are confronted by the obstacles on a daily basis giving a unique insight into the root causes of the problem. Whilst it has been acknowledged as a problem in the UK and a field which is currently under-researched the findings from this research can provide the basis for further research exploring the ideas put forward from this study and the development of interventions to improve EOLC in the ED. It is important to note that within

this study the barriers explored were of huge importance as this is what the interventions have been based on, under the assumption that if we can address the main obstacles in EOLC in turn this can improve the situation.

The study advocates the implementation of a 'pathway' within the ED to guide and optimise care on admission to the ED at the EOL. Whilst this term is controversial at present, it refers to the patient journey from admission to the ED to the next step whether this is into the community, hospital admission or death. The RCP (2012) and EOLC strategy (2008) both recommended the use of the LCP however this is no longer in use therefore this is a chance to examine the provision of EOLC in the ED and develop a tool which addresses the needs of patients with terminal illness accessing the ED at the EOL. A universal document has been suggested to address patient needs throughout their illness recognising the requirement for individualised care at all points of contact with the healthcare system. It should advocate the use of ACP, AD and emergency contingency plans which can be utilised if admitted to the ED. Nevertheless the study recognises the difficulties faced with this type of documentation, specifically confidentiality and compliance. This could be hugely beneficial and therefore further research was proposed to develop this by using policies and guidelines in place in other specialties such as cancer care (RCP, 2012). Knowledge gaps were identified in the ED in regard to resources both in hospitals and community as well as the importance for appropriate education around any tool or pathway implemented in the ED.

The most significant finding within this study and the aspect that needs to be addressed before any intervention is put in place is the culture within the ED. There is recognition among ED providers that fundamentally the two are not conducive with one another, that essentially it does not belong in this '*life-saving*' environment. This is not to attack participants but an in bedded cultural attitude within the ED that sees the department as '*make or break*' environment when in fact each patient still requires a holistic approach with individual care needs being considered. Until this underlying culture and attitude towards EOLC is addressed it is unlikely the two will sit side by side comfortably. Which puts even more emphasis on development of an intervention or tool which on the one hand addresses barriers within the ED yet can neutralise and overcome the cultural attitude towards EOLC.

ED providers need to acknowledge that they play a pivotal role in the provision of EOLC working in an area that represents a safe place where expert care will be provided quickly easing suffering and distress. Embracing and advocating change within this department can make a valuable difference to patients and families at the EOL. A quote from one of the participants shows how we need to consider EOLC in the ED and the importance of getting EOLC right:

*“It is about alleviating symptoms at the EOL, supporting family and friends and you only die once and it is important to get that as right as we possibly can” (PC CNS).*

## **5.6 Further Research**

More research in this field needs to be carried out promptly; statistics are showing that more people at the EOL will access the ED and that more people will require PC in this environment (Gott et al., 2013; Buckingham et al., 2008). The development of an intervention aimed to address culture, with a focus on education is essential; Diagram 6 outlines the next layer of research.

### **Diagram 8 – Program for Future Research**

- Observational Studies to examine whether culture is present in other ED, considering interventions that could assist in neutralising culture.
- Audit within the ED to identify specific reasons why people are accessing the ED at the EOL within the UK. This may help to address the problem that EOLC does not belong in the ED if we have current statistic and quantitative evidence to demonstrate the problem. Whilst this study was undertaken there was minimal statistics available on this topic as it is very difficult to ascertain due to the four hour window patients have in the ED and they move onto to a different area within hospitals classed as the same admission. This data could provide new and up-to-date statistics on the problem.
- Development of tool for implementation in the ED that aids EOLC based on observational studies that address the culture.
- Feasibility trial to test tool or interventions looking at specific outcome measures in different ED
- Integration of HCP in focus groups of all medical specialities including PC nurses, ED staff and ED doctors to aid the development of a tool/intervention which can be used by all HCP.
- Development of universal documentation within the ED and community for patients with terminal-illnesses. Liaise with HCP in the ED and within the community to set priorities of what needs to be included in this documentation and the problems encountered at present and how to overcome these by using the documentation.
- Development of educational tool to aid staff in the ED to help acknowledge the EOLC

## 6. Conclusion

The aim of this study was to explore ED staff views of EOLC and whether interventions could improve the standard of EOLC in the ED. This was done through a set of focus groups within the ED; the data was then subject to a form of thematic analysis with main themes and key findings becoming apparent. The study has answered and addressed all elements within the research question (Diagram 1) providing valuable data that not only illustrates a need to improve the situation but a platform in which to do so. ED providers felt there were barriers present that hindered EOLC in the ED; the environment, lack of documentation and different priorities. Whilst the groups looked to explore PC in the ED, there was generally very little distinction made between EOLC and PC and the terms were used interchangeably. Participants focussed on patients that were imminently dying in terms of EOLC and the PC team rather than the physical PC given to patients. Moreover the focus is on those coming into the ED at the EOL therefore more relevance to providing and improving the care to those who are imminently dying.

Interventions were identified through a comprehensive literature search which has been continuously conducted throughout the project so any new data obtained can contribute to findings. The interventions provided a basis for discussion within the focus groups as well as aiding development of future interventions. ED providers views were obtained on EOLC which were mainly negative, as were their views on established interventions, putting forward other interventions which they felt could improve EOLC; a patient pathway, universal documentation and education. Included in these interventions was the need for them to be 'clear, concise' and reflective of how ED staff work in this environment.

An additional finding not anticipated within the initial aims and objectives was the culture present within the ED that EOLC does not belong there, whilst other studies have picked up on the feasibility of EOLC in the ED an underlying culture has not been explored. The interventions therefore not only need to address the barriers but overcome the cultural barrier. Further observational studies are required to identify whether this is present in other ED and construct an intervention or process which can address all of these factors identified. EOLC is becoming an international concern and pioneering area of research whilst interventions mainly appeared in the US there is a need to consider this issue in a wider field exploring Europe and Australia and whether interventions are applicable to a worldwide setting.

This study has provided a platform in the UK from which further research can begin to expand on the ideas and recommendations put forward to improve EOLC in this setting. Further research is imperative in this field as statistics suggest people will continue to access

the ED at the EOL and this is a difficult time for patients and families that can only be done once but leave a lasting memory.

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## **Appendix 1 – Definitions**

### **Palliative Care (PC)**

The World Health Organisation (WHO) defines PC as ‘an approach that improves the QOL 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’ (WHO, 2013). Any patient who is suffering from a terminal or life-limiting illnesses qualifies for PC where the primary goal of care is QOL (DeVader et. al, 2012).

PC is ideally initiated on diagnosis of a serious illness that requires symptom management, complex decision-making, psychosocial and spiritual support involving both patient and relatives (Smith et al.,2009). This should continue with the patient receiving high quality PC throughout the disease process at each entry to the healthcare system (Quest et al.,2011). The quality of PC can be measured in the patients symptom management and family perception of their loved ones death (DeVader et al.,2012).PC has been shown to improve

patient's symptoms and increase QOL throughout their disease and at the EOL allowing relatives and family to grieve and avoid the shock of an unexpected traumatic death (Milligan, 2009).

### End-Of-Life Care (EOLC)

The WHO defines EOLC as ‘an essential part of PC where patients’ health status is dramatically declining and refers to the care given in the last few days or weeks of life’ (WHO, 2013a). A distinction has been made between PC and EOLC as we see PC as something that can be offered alongside life sustaining treatment and EOL being viewed as the point where comfort is the top priority for the patient – looking at preferred place of care and eventually death.

### Terminal or Life-Limiting Illnesses

Defined as ‘a condition or illness from which the patient will eventually die from’ (WHO, 2013b) this includes but is not contained to advanced malignancies e.g. cancers, advanced heart disease and COPD. It has been chosen as statistics show an increase in admissions to the ED of this population group but other studies show concerns surrounding care there are receiving on admission to the ED (Bailey et al.,2011a).

### Appendix 2 - Search Strategy

CLINHAL	
1. Emergency Department AND Palliative Care AND End of Life Care	0 results
2. Emergency Department AND Palliative Care	85 results – 11 relevant
3. Palliative Care Interventions	41 results – 0 relevant
4. Palliative Care Interventions and Emergency Department	0 results
5. Palliative Care and Emergency Department and Improvement	7 results – 4 relevant
<b>Relevant articles (11)</b>	
<ol style="list-style-type: none"> <li>1. Lawson (2009) Can an introduction of a integrated palliative care service model improve existing palliative care services and impact ED visits? <b>Journal Palliative Medicine</b>, 12:3:245</li> <li>2. Stone (2006) Lack of pain assessment for Cancer patients presenting to ED with complaints of pain; Can it be improved by simple intervention? <b>Journal Palliative Medicine</b>, 9:1:7</li> <li>3. Glajchen et, al. (2011) A rapid two stage screening protocol for palliative care in the Emergency Department; A quality improvement Initiative, <b>Journal of pain and symptom management</b>, 42:5:657,</li> <li>4. Smith et, al. (2009) Am I doing the right thing? The provider perspective on improving</li> </ol>	

palliative care in the ED, **Annals of Emergency Medicine**, 54:1:86

5. Grudzen et, al. (2011) The palliative care model for emergency department patients with advance illness, **Journal of Palliative Medicine**, 14:8:945
6. Richards (2011) Palliative Care symptom assessment of patients with cancer in the ED; validation of the screen for palliative and end of life care needs in the emergency department instrument, **Journal of palliative medicine**, 14:6:757
7. Lurkin (2012) Palliative care in the emergency department; an oxymoron or just good medicine? **Emergency Medicine Australia**, 24:102
8. Baiktas et, al. (2009) Effects of palliative care interventions on clinical outcomes in patients with advance cancer, **JAMA**, 302:7:741
9. Quest et, al. (2011) Research Priorities for Palliative and end of life care in the emergency setting, **Academic Emergency Medicine**, 18:6:70-76
10. Rondeau (2009)
11. Chan (2004) end of life care model s and emergency department care, **Academic Emergency Medicine**, 11:1:79

<b>MEDLINE</b>	
<b>1. Emergency Department AND Palliative Care AND End of Life Care</b>	<b>0 results</b>
<b>2. Emergency Department AND Palliative Care</b>	<b>83 results – 8 relevant</b>
<b>3. Palliative Care Interventions</b>	<b>45 results – 0 relevant</b>
<b>4. Palliative Care Interventions and Emergency Department</b>	<b>83 results – 9 relevant</b>
<b>5. Palliative Care and Emergency Department and Improvement</b>	<b>4 results – 2 relevant</b>
<b>Relevant Articles (8)</b>	
<ol style="list-style-type: none"> <li>1. Glajchen et, al. (2011) A rapid two stage screening protocol for palliative care in the Emergency Department; A quality improvement Initiative, <b>Journal of pain and symptom management</b>, 42:5:657</li> <li>2. Grudzen et, al. (2011) The palliative care model for emergency department patients with advance illness, <b>Journal of Palliative Medicine</b>, 14:8:945</li> <li>3. Quest et, al. (2011) Research Priorities for Palliative and end of life care in the emergency setting, <b>Academic Emergency Medicine</b>, 18:6:70-76</li> <li>4. Richards et, al. (2011) Palliative Care symptom assessment of patients with cancer in the ED; validation of the screen for palliative and end of life care needs in the emergency department instrument, <b>Journal of palliative medicine</b>, 14:6:757</li> </ol>	

5. Baiktas et, al. (2009) Effects of palliative care interventions on clinical outcomes in patients with advance cancer, **JAMA**, 302:7:741
6. Smith et, al. (2009) Am I doing the right thing? The provider perspective on improving palliative care in the ED, **Annals of Emergency Medicine**, 54:1:86
7. Rondeau (2009)
8. Chan (2004) end of life care model s and emergency department care, **Academic Emergency Medicine**, 11:1:79

<b>Cochrane Library</b>	
<b>1. Emergency Department AND Palliative Care AND End of Life Care</b>	<b>0 results</b>
<b>2. Emergency Department AND Palliative Care</b>	<b>4 results – 1 relevant</b>
<b>3. Palliative Care Interventions</b>	<b>38 results – 0 relevant</b>
<b>4. Palliative Care Interventions and Emergency Department</b>	<b>4 results – 1 relevant</b>
<b>5. Palliative Care and Emergency Department and Improvement</b>	<b>2 results – 1 relevant</b>
<b>Relevant Articles (1)</b>	
1. Baiktas et, al. (2009) Effects of palliative care interventions on clinical outcomes in patients with advance cancer, <b>JAMA</b> , 302:7:741	

<b>AHMED</b>	
<b>1. Emergency Department AND Palliative Care AND End of Life Care</b>	<b>0 results</b>
<b>2. Emergency Department AND Palliative Care</b>	<b>27 results – 3 relevant</b>
<b>3. Palliative Care Interventions</b>	<b>170 results</b>
<b>4. Palliative Care Interventions and Emergency Department</b>	<b>2 results – 1 relevant</b>
<b>5. Palliative Care and Emergency Department and Improvement</b>	<b>1 results – 1 relevant</b>
<b>Relevant Literature (3)</b>	
1. Baiktas et, al. (2009) Effects of palliative care interventions on clinical outcomes in patients with advance cancer, <b>JAMA</b> , 302:7:741	
2. Stone (2006) Lack of pain assessment for Cancer patients presenting to ED with complaints of pain; Can it be improved by simple intervention? <b>Journal Palliative Medicine</b> , 9:1:7	
3. Lawson (2009) Can an introduction of a integrated palliative care service model improve existing palliative care services and impact ED visits? <b>Journal Palliative Medicine</b> , 12:3:245	

<b>BNI</b>	
<b>1. Emergency Department AND Palliative Care AND End of Life Care</b>	<b>0 results</b>
<b>2. Emergency Department AND Palliative Care</b>	<b>5 results – 1 relevant</b>
<b>3. Palliative Care Interventions</b>	<b>241 results</b>
<b>4. Palliative Care Interventions and Emergency Department</b>	<b>0 results</b>
<b>5. Palliative Care and Emergency Department and Improvement</b>	<b>1 result – 2 relevant</b>
<b>Relevant Literature (1)</b>	
<ol style="list-style-type: none"> <li>1. Glajchen et, al. (2011) A rapid two stage screening protocol for palliative care in the Emergency Department; A quality improvement Initiative, <b>Journal of pain and symptom management</b>, 42:5:657</li> <li>2. Beckstrand et, al. (2012) Emergency Nurses suggestions for improving end of life care obstacles, <b>Journal of Emergency Nursing</b>, 38:5:7</li> </ol>	

<b>ProQuest</b>	
<b>1. Emergency Department AND Palliative Care AND End of Life Care</b>	<b>0 results</b>
<b>2. Emergency Department AND Palliative Care</b>	<b>262 results</b>
<b>3. Palliative Care Interventions</b>	<b>14003 results</b>
<b>4. Palliative Care Interventions and Emergency Department</b>	<b>12 results – 5 relevant</b>
<b>5. Palliative Care and Emergency Department and Improvement</b>	<b>9 results – 1 relevant</b>
<b>Relevant literature (5)</b>	
<ol style="list-style-type: none"> <li>1. Baiktas et, al. (2009) Effects of palliative care interventions on clinical outcomes in patients with advance cancer, <b>JAMA</b>, 302:7:741</li> <li>2. Smith et, al. (2009) Am I doing the right thing? The provider perspective on improving palliative care in the ED, <b>Annals of Emergency Medicine</b>, 54:1:86</li> <li>3. DeVader (2012) Initiating Palliative Care in the emergency department, <b>Journal of Emergency Medicine</b>, 43:5:803</li> <li>4. Grudzen et, al. (2011) The palliative care model for emergency department patients with</li> </ol>	

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5. Richards (2011) Palliative Care symptom assessment of patients with cancer in the ED; validation of the screen for palliative and end of life care needs in the emergency department instrument, **Journal of palliative medicine**, 14:6:757

**Appendix 3 – Article Summary Table (Adapted from CASP checklist and Gerish and Lacey, 2010)**

Title, Author and Date	Main Aim	Data Collection	Main Findings	Recommendations and implications for further practice	Strengths and weaknesses
<p>Smith et, al. (2009) Am I doing the right thing? Provider perspective on Improving palliative care in the ED</p>	<p>Explore attitudes, experiences and beliefs of emergency providers about palliative care in the ED using structured qualitative methods</p>	<p>3 focus groups of physicians, nurses, social workers and technicians.</p> <p>A grounded theory approach was used to code responses, resolving discrepancies by consensus</p>	<p>Six themes was discovered;</p> <ol style="list-style-type: none"> <li>1. Palliative care is EOLC</li> <li>2. Feasibility of PC in ED</li> <li>3. Families distressed by symptoms at EOL</li> <li>4. Lack communication</li> <li>5. Conflict about withholding life prolonging treatment</li> <li>6. Training in pain management inadequate</li> </ol> <p>Seven principal obstacles providing palliative care in the ED.</p> <ol style="list-style-type: none"> <li>1. PC not a major focus in ED</li> <li>2. Emotional challenges</li> <li>3. Not being able to act – frustrating</li> <li>4. Environment not appropriate</li> <li>5. Do not know patients</li> <li>6. PC needs are of a lower priority</li> <li>7. Long ED waiting times</li> </ol> <ul style="list-style-type: none"> <li>• Explored definition of what palliative care is most equated it with an effort to reduce symptoms in patients that were dying referred to as comfort care.</li> <li>• Multiple attitudinal and structural barriers to provision of palliative care in the ED.</li> <li>• No documentation about outpatient communication regarding goals of care and uncertain what conversations took place – when did it fall to ED providers to have these conversations.</li> <li>• Lack of communication and documentation as major factors in mistaken resuscitation.</li> <li>• Physicians felt compelled to resuscitate even though not in best interest of patient</li> <li>• Primary focus should be on communication and documentation improvements in outpatients discussing goals</li> </ul>	<p>Future studies should focus on;</p> <ul style="list-style-type: none"> <li>• Improving communication and documentation about goals of care.</li> <li>• Improving skills in communication and symptom management</li> </ul>	<p>Strengths;</p> <ul style="list-style-type: none"> <li>• Achieved aim to generate a hypothesis and provide a better focus for future research.</li> </ul> <p>Limitations;</p> <ul style="list-style-type: none"> <li>• Limited generalizablity as only undertaken in two hospitals may not reflect views of those working in other hospitals in other states or places.</li> <li>• Participants had mean experience of 2.5 clinical years</li> <li>• Small sample size</li> <li>• Selection bias – people who view palliative care in better light more likely to take part</li> </ul>

			<p>of care.</p> <ul style="list-style-type: none"> <li>• Physicians described similar to oncology helpline a palliative care helpline</li> <li>• Intervention to rape crisis where nurses were trained to provide excellent care and called on as needed. "Palliative care champions" – trained emphasising communication, pain and ethics.</li> <li>• Improving communication skills training</li> </ul>		
Clarke (2008) Improving end of life care in ED	Explore how end of life care can be improved in the ED	Narrative Review	<ul style="list-style-type: none"> <li>• Sudden deaths occur in the ED more than any other department in the healthcare system however not designed to provide EOL care.</li> <li>• Caring for patients with traumatic injuries requires a different set of skills than caring for patient with long term illness</li> <li>• High tech and face past of the ED are suggested to be unsuitable for EOL care in the ED</li> </ul> <p>Barriers;</p> <ul style="list-style-type: none"> <li>• Staff shortages</li> <li>• Poor ED design</li> <li>• Pressure to reduce length of stay in the ED</li> <li>• Lack of rapport and trust –</li> <li>• Limited information about patient available</li> </ul> <p>Improvement suggestions;</p> <ul style="list-style-type: none"> <li>• Must involve collaboration of all HCP</li> <li>• Advance directives being used can guide HCP to make appropriate decisions</li> <li>• Patient and family involvement – must all play active role in EOL decision-making</li> <li>• EOL protocols – guide HCP in provision of consistent and individualised care, few have been designed specifically for the use in EOL care focus on symptom control, grief responses, communication and incorporated into training.</li> <li>• Nurses input – advocates for patients need to take active</li> </ul>	<ul style="list-style-type: none"> <li>• Undertake research specifically on care issues in ED</li> <li>• Development of EOL care protocols specific to the ED.</li> <li>• Education should be initial step in policy change and development. Increase consistency and continuity as well as adequately training staff.</li> <li>• Resource teams approachable experts who can educate and support in the provision of end of life care.</li> </ul>	<p>Strengths;</p> <ul style="list-style-type: none"> <li>• Highlights barriers and improvement strategies clearly</li> </ul> <p>Weaknesses;</p> <ul style="list-style-type: none"> <li>• Undertaken in the USA some components not used e.g. advance directives do not tend to be used as commonly in UK.</li> </ul>

			roles in EOL care beginning of good EOL care starts with communications with patient and family.		
Devader et, al. (2012)Initiating Palliative care in the ED	Using illustrative cases to discuss important concepts in palliative care in relation to the ED.		Introduces the rapid palliative assessment composed of secondary survey of ABCD's; A) Does the patient have any advance directives (AD)? B) How can you make the patient feel better? C) Are there caregivers by the bedside? If not how can you reach them? D) Does the patient have decision making capacity? Authors suggest this should be the assessment used in ED when palliative patients present there. • Palliative care is under-utilised • Benefits of AD – poorly documented and utilised by patients Shows better acceptance of diagnosis and no increased feelings of sadness or depression. Family coped with grief a lot better if EOL decisions had been discussed.	Future studies need to focus on • implementing palliative care teams in the ED, • whether palliative care referrals improve patients Quality of Life (QOL) and decrease ED visits • How attitudes towards PC can be changed with education and experience in Palliative care	Strengths; • Suggests an assessment tool • Examines cost implications of healthcare system but to patients and families. Other studies have been unable to do this. • Explores palliative care implications on patients and families Weaknesses; • Study took place in USA therefore differences in healthcare system • No Validity undertaken on assessment tool
Beckstrand et, al. (2012)Emergen cy Nurses Suggestions for Improving End of life care Obstacles	What aspects of end of life care would emergency nurses change to improve how patients die in an ED?	Postal survey 1000 nurses received survey, response rate 441  Inclusion criteria and pilot study completed.	Overwhelming consistency in results and 5 major themes identified; 1. Increase amount of time and availability of nurses who have to care for dying patients. – requires time and presence to educate and support family. Staffing limitations and nursing needs of other patients decreased ability to provide optimal care to dying patients. 2. Family presence during resuscitation – for patient and family to be together in last moments. 3. More comfortable patient rooms – need better designed ED	Future studies looking at methods that redistribute nurse's workload to increase amount of direct care to dying patient.  Making changes to the ED design and processes to facilitate dignity and privacy for the dying patient in the	Strengths • Good response rate. • National random sample. • Gains in depth understanding of nurses views on how to improve EOLC in the ED.

			<p>provide space for patient and family allowing for enhanced privacy.</p> <ol style="list-style-type: none"> <li>4. Provide more privacy at the end of life</li> <li>5. Family grief room</li> </ol> <p>Minor themes were; increased ancillary staff involvement so nurse can focus on the patient, managing pain and minimising suffering – comfort medications should never be withheld due to side effects. Family education. Upholding advance directives – documentation not always available, supporting patient’s decisions can also be hard on family.</p> <p>Early initiation of palliative care through improved training and referral to palliative care teams.</p>	<p>ED, whilst this is an expensive and long term implications.</p> <p>Nurses could look at their department and identify potential change in layout and patient flow that could improve this aspect of care.</p>	<p>Limitations</p> <ul style="list-style-type: none"> <li>• Response rate only obtained from emergency nurses so only able to apply to emergency nurses who are members of ENA.</li> <li>• Some responses not legible and did not make sense.</li> </ul>
Grudzen et, al. (2011) The palliative care model for emergency department patients with advanced illness,	Narrative review	Exploring Palliative care services in the ED	<p>It is important to develop theoretical models of care delivery that are based on patient needs, as opposed to just allowing delivery to grow organically based on what services are available.</p> <p>Several medical centres have recently initiated pilot programs to deliver ED-based palliative care consultation.</p> <ol style="list-style-type: none"> <li>1. Palliative care service initiated programs <ul style="list-style-type: none"> <li>• Significant staff and resources are needed to start this</li> <li>• Early data suggests that it can help to identify patients with palliative care needs and provide needed services.</li> <li>• In two of the programs it has shown ED based consultation has decreased hospital stay and costs to those who are admitted and die in hospital.</li> <li>• There has been increased use of palliative care services and increased links with hospices.</li> <li>• There has been one team which participate in ED staff meetings and make regular ED visits resulting in successful partnership 9.2% admissions and 66.7% all direct admissions to palliative care come from ED.</li> </ul> </li> <li>2. Palliative care Champions <ul style="list-style-type: none"> <li>• An emergency physician trained in palliative medicine began a pilot program to increase emergency department-based palliative care consultations.</li> </ul> </li> </ol>	<p>The number of ED-based pilot programs in the United States continues to rise.</p> <p>Preliminary data show associated reductions in hospital length of stay, costs per day.</p> <p>From a quality and cost-benefit perspective, offering p/c services in the ED, at the beginning, might provide even greater benefit to patients, families and hospitals than inpatient consultation, which often occurs late in a patient’s hospital course.</p>	<p>Strengths;</p> <p>Uses evidence some other studies to show effectiveness of interventions.</p> <p>Explores barriers and potential problems that may affect the success of the interventions</p> <p>Limitations;</p> <p>Examples of interventions are all in the United States, completely different healthcare systems.</p> <p>All interventions in early stages due to lack of</p>

		<p>3. Links to hospice</p> <ul style="list-style-type: none"> <li>• Patients may benefit from active partnerships between ED and hospices, especially those patients at the end of life with clear goals of care and a high burden of symptoms.</li> <li>• The ED at Stands Hospital in Florida works closely with a community hospice to identify patients with end-stage illness whose pain and symptoms can be managed in the outpatient setting.</li> <li>• The hospice provides 2 full-time nurses from 7:00 am to 11:00 assist the ED in identifying eligible patients reviewing hospice benefits.</li> <li>• While data is preliminary, the program is considered highly successful by hospital administrators and ED staff, and an increasing number of patients are discharged with hospice services</li> </ul> <p><i>Barriers</i></p> <ul style="list-style-type: none"> <li>• ED workers do not feel their role is to provide palliative care Feel it is not their role to discuss goals of cares and should be address before this point. Nursing staff typically supportive of p/c – nurse led palliative care/initiate palliative care.</li> <li>• Limited staffing of palliative and ED workers Ideally p/c staff available 24/7 in ED however not feasible so ED will need to put in place a care team. In these situations acute beds maybe way clear beds for patients with symptom relief.</li> </ul> <p><i>Potential expansion programs</i></p> <ul style="list-style-type: none"> <li>• Training emergency providers in p/c delivery– a way to ensure uniform access to p/c. EPEC-EM curriculum educates essential in p/c; includes rapid assessment of palliative care needs and appropriate referral to hospice. All HCP provide minimal p/c for ED staff treat common symptoms, addressing goals of care.</li> <li>• Triggered consultations – way to overcome lack of knowledge. Triggers have been developed in ICU’s for appropriate patient referrals to a specialised team. Could be built into electronic record that could opt out or decline. Need to involve HCP involve in care regularly of patients require p/c input</li> <li>• Business Case – Palliative care has been shown to significantly</li> </ul>		<p>research done on this subject true outcome unknown. Initial results however all are showing that interventions are successful.</p>
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			<p>improve patient and family QOL while at the same time improving patient and caregiver satisfaction and reducing distressing symptoms, reducing hospital length-of stay and cost per day. Most interestingly, early palliative care consultation for patients with metastatic cancer has also been shown to reduce mortality.</p> <ul style="list-style-type: none"> <li>• Preliminary data shows that moving p/c referral to the ED rather than later in hospital stay can reduce hospital stay study in Detroit show that those with p/c in ED had a shorter stay in hospital.</li> </ul>		
<p>Glajchen et, al. (2011) A rapid two stage screening protocol for palliative care in the ED; A quality improvement initiative, Journal of Pain and symptom management</p>	<p>Address the needs of elderly patients and explore feasibility of rapid screening and referral in the ED for palliative care services.</p>	<p>A full time key worker was placed in the ED and a rapid two stage screening protocol developed to identify needs among patients &gt;65yrs</p> <p>Briefpal protocol included screening tool designed for the project;</p> <ul style="list-style-type: none"> <li>• Karnofsky performance scale</li> <li>• Functional assessment staging tool</li> <li>• Memorial Symptom assessment</li> </ul>	<p>Intervention</p> <p>Stage 1 – elderly patients with life limiting conditions were identified by the social worker. Conditions involved dementia, CHF, COPD, advance malignancy, AIDS with at least moderate functional status limitations.</p> <p>Stage 2 – subgroups with recent losses in ADLS, high symptom distress, poor functional status and high levels care giver burden were identified.</p> <ul style="list-style-type: none"> <li>• The social worker administered tools face to face and identified appropriate patients. Referrals were made to hospice from both groups.</li> <li>• From this referral process streamlined, laminated card referral criteria was developed and a referral hotline installed.</li> <li>• Palliative care training given to all those working in the ED.</li> <li>• Local ED champions identified and physicians then did own screening.</li> </ul> <p>Outcomes</p> <ul style="list-style-type: none"> <li>• Of patients 144 met illness criteria, 140 met further functional decline and 51 in need palliative care, 5 patients referred to hospice and 46 referred to specialist level palliative care.</li> <li>• Patients lost average of 18% of ADLs within 3 months.</li> <li>• Pain was most common symptom, SOB, nausea, lack of appetite and weight loss other common symptoms.</li> <li>• Comparing the referral and non referral group both patients were similar but referral group had higher rates cancer, higher</li> </ul>	<p>Found within the ED there were unmet symptoms, functional and care giver needs which suggest that ED provides unrealised opportunity to address this to improve EOLC.</p> <p>Showed feasibility of successful screening, value staff education, importance of trained champions with staff embracing champion role.</p> <p>Demonstrates that both palliative care and ED medicine operate differently successful collaboration can occur and referral process can be streamlined within an environment of acute clinical needs and good response times.</p>	<p><i>Strengths</i></p> <p>Study was able to show improvement due to the interventions put in place and identify trends where referrals went down. Identified barriers.</p> <p><i>Limitations</i></p> <p>A small number of people were unreachable due to telephone disconnection suggests higher death rate. Data from non referral group was harder to collect and unable to report on that group. Palliative care service was understaffed and in flux during project which could have effected management of new referrals.</p>

		<p>scale</p> <ul style="list-style-type: none"> <li>• Katz ADLs</li> <li>• Brief assessment scale for caregivers.</li> </ul> <p>Barriers identified by field notes and observations</p> <p>1587 patients &gt;65yrs were screened in the ED over 8 months.</p>	<p>functional loss and higher care giver burden.</p> <ul style="list-style-type: none"> <li>• Follow up phone calls made to 112 patients referred. Those who received palliative care had reduction in symptoms.</li> <li>• At its peak the Briefpal project accounted for half of all referrals to palliative care</li> <li>• Peak in referrals was when key worker was present full time in the ED and after staff education. Referrals decline when she was away.</li> </ul> <p><i>Barriers</i></p> <p>Reluctance to refer by the primary care physician accounts one half of non referred groups. Reasons included fear involving p/c, misunderstanding p/c and hospice and belief they were already doing palliative care. System barriers included lack understanding about palliative care and hospice and hesitation about involving p/c.</p>		<p>Dip in referrals can be accounted for by high staff turnover in addition funding and communication can slow response time to referral.</p>
<p>Quest et, al. (2011) Research priorities for palliative and end of life care in the emergency setting, Academic Emergency Medicine</p>	<p>Research priorities for palliative and end of life care in the emergency setting – propose a research agenda for studying the integration of palliative care in the ED setting</p>	<p>Authors Manuscript</p>	<p>Emergency clinicians have reported they feel uncomfortable assessing and directing care of a patient who is nearing the end of life and unsure of the role of emergency clinician at this time. Identified 4 questions for p/c and emergency medicine research:</p> <ol style="list-style-type: none"> <li>1. Which patients are in needs of palliative care</li> <li>2. What is optimal role for emergency clinicians caring for patients with terminal illness</li> <li>3. How does integration and initiation of palliative care training and services effect healthcare utilization</li> <li>4. What are educational priorities for emergency providers in p/c?</li> </ol> <p>Data suggests that ED nurses and physicians feel unprepared to meet palliative care needs of patients and families with some questioning the role of palliative care. ED must define the role of ED clinicians and ensure they can work comfortably providing palliative care that is appropriate to the ED.</p> <p>Many feel that management of patients near the end of life is</p>	<p>Integration of palliative care into the ED will need a shift in care delivery where palliative care becomes routine in emergency practice supported by interventions.</p> <p>ED can serve as a critical link to identify patients in need of palliative care. It is strongly recommended that screening tools and markers are developed with goal of identifying interventions that manage pain and suffering of patients and relatives.</p>	<p><i>Strengths</i></p> <p>Identifies questions for further research and barriers to optimal care</p> <p>Identifies what needs to be focussed on to improve care</p> <p><i>Limitations</i></p> <p>Again the study has taken place in the US so research priorities maybe different however they can still be applied to this study as basic need for palliative care in the ED remains constant.</p>

			<p>inappropriate in the ED. Many feel once patient is in the ED that life extending therapies are desired maybe accounting for physicians views that it is not a setting in which goals of care should change. Need the ED setting to be seen as an opportunity to take action to initiate ED based palliative care interventions. Need to consider how palliative care can support needs of emergency care:</p> <ul style="list-style-type: none"> <li>• Ensure current documentation for patient and a clear patient centred plan is in place.</li> <li>• Core competencies for ED practitioners provided HCP knowledge and skills deliver care to patients in need of palliative care in the ED.</li> <li>• Initiation or completion AD</li> <li>• Standardised documentation templates that define goals of care</li> <li>• Direct transfer from ED to hospice/palliative care services – links with community and hospices.</li> <li>• Need for an identification tool supporting decision if people need palliative care input.</li> </ul>		
Richards et, al. (2011) Palliative Care Symptom Assessment for Patients with Cancer in the Emergency Department: Validation of the Screen for Palliative and	Develop and validate a novel palliative medicine needs assessment tool for patients with cancer in the emergency department.	Observational cohort study was used to compare the performance of a palliative care symptom assessment tool to domains of the previously validated NEST	<p>The SPEED instrument is the first comprehensive symptom assessment tool validated for use with emergency department patients that have palliative or EOL care needs. The SPEED instrument is a brief, multidimensional symptom assessment tool designed to be comprehensive, yet rapid in the assessment of domains of palliative care in an emergency department. Intended to assist ED providers with a brief comprehensive “first-pass” assessment that allows the identification of palliative needs that likely require intervention either in the emergency department, as an inpatient, or in follow-up. This study shows that respondents’ answers to SPEED scale items</p>	Further studies are required to elucidate the therapeutic and operational implications of screening for palliative care needs of such patients. Specifically, the operational implications of administrating the SPEED tool needs to be further clarified Need to look at the application to non-cancerous	<p>Strengths;</p> <ul style="list-style-type: none"> <li>• Tool deemed to have face validity</li> <li>• Previous tools developed in oncology and palliative care settings, SPEED was developed by emergency medicine and palliative specialists.</li> </ul>

End-of-Life Care Needs in the Emergency Department Instrument		tool	<p>correlate well with those items on previously validated symptom assessment tools, across several domains. This indicates that the SPEED instrument is a valid tool to comprehensively, but efficiently assess the palliative care needs of oncology patients presenting to the ED.</p> <p>The SPEED tool is designed to be administered in a quick and efficient manner by all levels of emergency department provider, including physician, nurse, chaplains, and social work.</p> <p>However, this study demonstrates that the SPEED screening tool is valid to screen for palliative care needs of the oncology patient presenting to the ED</p>	chronic illness.	<ul style="list-style-type: none"> <li>• Can be used by MDT</li> </ul> <p>Weaknesses;</p> <ul style="list-style-type: none"> <li>• Only looks at oncology patients in the ED.</li> </ul>
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**Appendix 4 – Comparison of NEST and SPEED by Item Domain and Question (Richards et, al. 2012).**

<b>Comparison of NEST and SPEED by Item Domain and Question</b>	
<b>NEST</b>	<b>SPEED</b>
<b>Social</b>	
1. How much of a financial hardship is your illness for you or your family? 2. How much trouble do you have accessing the medical care you need? 3. How often is there someone to confide in? 4. How much help do you need with things like getting meals or getting to the doctor?	1. How much difficulty are you having with your medication (for example, obtaining medications, knowing how or when to take them, managing side effects)? 2. How much difficulty are you having getting outpatient follow-up (for example, transportation, arranging, making or forgetting appointments)? 3. How much difficulty are you having getting your care needs met at home (for example, bathing, dressing, and meals)?
<b>Therapeutic</b>	
1. How much do you feel your doctors and nurses respect you as an individual? 2. How clear is the information from the medical team about what to expect regarding your illness? 3. How much do you feel that the medical care you are getting fits with your goals?	How much difficulty are you having communicating with your doctors about your care preferences? 2. How much difficulty are you having with the care your clinical team is providing? 3. How much difficulty are you having getting medical care that fits with your goals?
<b>Symptom Matters Physical</b>	<b>Physical</b>
1. How much do you suffer from physical symptoms such as pain, shortness of breath, fatigue, bowel, or urination problems? 2. How often do you feel confused or anxious or depressed?	1. How much are you suffering from pain? 2. How much are you suffering from shortness of breath? 3. How much are you suffering from other physical symptoms?
	<b>Psychological</b>
	1. How much are you suffering from anxiety? 2. How much are you suffering from depression? 3. How much are you suffering from feeling overwhelmed?
<b>Existential Spiritual</b>	<b>Spiritual</b>
1. How much does this illness seem senseless and meaningless? 2. How much does religious belief or your spiritual life contribute to your sense of purpose? 3. How much have you settled your relationship with the people close to you? 4. Since your illness, how much do you live life with a special sense of purpose?	2. How much does this illness seem senseless or meaningless?

## Appendix 5 - Interview guide

Questions	Total Focus group time 90mins Time for each section approx.
<p>Introduce observer and moderator, names and background. Explain research question and purpose of today to discuss palliative care and end of life in the ED. Remind everyone about confidentiality, there is not a wrong/right answer, want honest answers, opinions, views, remaining professional and confidential if any examples of practice are used.</p>	5mins
<p>Starter for group to interact and set up the focus group</p> <ul style="list-style-type: none"> <li>• Go around introduce everyone and roles and explain what you feel is meant by palliative care and End Of Life Care (EOLC)?</li> <li>• Is there a difference?</li> <li>• Give pre set definitions of palliative care and EOL</li> <li>• Reactions to definition/comments/disagreements</li> </ul> <p><i>This is to set the scene up for participants. Cote-Arsenault and Beedy (1999) suggest that first question should be neutral and simple so everyone can interact and get to know others in the group.</i></p>	10 mins
<p>Patients entering the ED with terminal conditions or chronic illness what are people's experiences of palliative care within the ED? Experiences of EOLC.</p> <ul style="list-style-type: none"> <li>• Experiences good/bad – reflect on why?</li> <li>• Can you identify patients in need of palliative care or at the EOL in the ED? How?</li> <li>• What are the goals of care for patients at the end of life? How do they differ from other patients?</li> <li>• Are there barriers in the ED which prevent palliative care happening? What are they?</li> </ul> <p><i>The literature suggests that there are barriers within the ED that prevent adequate palliative care happening, however all these studies have been mainly conducted in the USA and so cannot directly apply them to the UK due to different healthcare systems. Start to think about EOLC they give as HCP and how it can be improved.</i></p>	20mins
<p>Having thought about barriers to palliative care in the ED, any suggestions to how this could be improved?</p> <ul style="list-style-type: none"> <li>• How can end of life care be improved in the ED?</li> </ul>	20mins
<p>Hand out palliative care interventions that seek to improve end of life care in the ED from barriers identified in literature. Discuss interventions individually in terms of feasibility, problems, impact on care, workload;</p> <ul style="list-style-type: none"> <li>• Palliative Care Champions/Link nurse</li> <li>• Screening Tool</li> <li>• Education and Training</li> <li>• Improved Documentation</li> </ul>	(5 mins to read handout)  35mins

# Two Stage Screening Protocol

## Identifies palliative care needs for those above age 65 years in the ED.

STAGE 1 – patients with life limiting conditions on admission to the ED were identified and referred to palliative care

STAGE 2- patients who presented to the ED with recent loss to ADL, high symptom distress, poor functional status and high levels of caregiver burden were referred.

- Key worker/palliative care champion present in ED to assist
- Palliative care advice hotline developed

# SPEED Tool

# ABCD Palliative Care

**A** Are there any **advance directives** in place?

**B** How can I make the patient feel **better**?  
Think about symptom control.

**C** Are there any **caregivers** at the bedside?  
How can I get hold of them?

**D** Does the patient have **decision making capacity**?

# Palliative Champions

- Specific training in symptom management, palliative ethics and communication.
- Links with hospice and hospital palliative care team
- Provides training and advice to others

# Documentation

- Electronic documentation – DNAR, EOL decisions
- Improved communication
- Better EOL discussions – documented clearly

## SOCIAL

- How much difficulty are you having with your medication?
- How much difficulty are you having getting outpatient follow-up?
- How much difficulty are you having getting your care needs met at home?

## THERAPUTIC

- How much difficulty are you having communicating with your doctors about your care preferences?
- How much difficulty are you having with the care your clinical team is providing?
- How much difficulty are you having getting medical care that fits with your goals?

## PHYSICAL

- How much are you suffering from pain?
- How much are you suffering from SOB?
- How much are you suffering from other physical symptoms?

## PSYCHOLOGICAL

- How much are you suffering from anxiety?
- How much are you suffering from depression?

# Education & Training

- Symptom management
- Communication – difficult situations, speaking to relatives and conflict
- Palliative training to those interested

## **Appendix 7 - Research protocol**

### **Background - Why is Palliative Care needed in the Emergency Department?**

The Emergency Department (ED) is associated with heroic actions, life saving, resuscitation and stabilisation of patients (Bailey, 2011). The main purpose of emergency medicine 'is to treat undifferentiated patients across age and disease or injury to create time restricted assessment of the patient, to resuscitate and stabilise in order to establish initial or definitive treatment and to discharge to an appropriate facility' (Foreno et. al, 2012). However due to an increase in the population within the UK and advances in medicine more people are living longer and an increasing number with terminal and chronic illnesses. These patients are increasingly accessing the ED for symptom control, acute changes in health status, end of life emergencies and caregivers who are unable to cope with the physical or psychological symptoms (Beckstrand et, al. 2012). For many of these patients aggressive therapies and active resuscitation actions are not appropriate or in line with their wishes. Instead they are seeking alleviation of distressing symptoms, comfort and support, and a requirement for palliative and end of life care in the ED (Grudzen et, al. 2012; Lawson, 2008).

In recent years there has been an increased amount of attention on end of life care within the NHS, with the end of life care strategy (DoH, 2008) promoting high quality end of life care, more choices regarding preferred place of care and death and provisions for what a good death would entail (DoH, 2008). The NHS end of life care program (2004-2007) set out gold standard frameworks, the Liverpool Care Pathway (LCP) and Preferred Priorities for Care (PPC). Despite these frameworks over half the complaints the NHS receive are regarding end of life care showing a need that there is still improvement needed (Milligan. 2009). The ED is a place where death frequently occurs, however no research or initiative have focussed on end of life care within the ED. The limited research conducted on end of life care within the ED continual supports concerns about poor end of life care within this setting (Bailey, 2011; Grudzen, Stone and Morrison, 2011; Devader, 2011).

The ED is a potentially an ideal place for excellent palliative and end of life care to take place. It is a gateway into the healthcare system used when the physical, social and psychological burden of both patients and caregivers maybe too high (Bailey, 2011; Quest, 2011). It could provide a critical link to identifying patients with terminal and chronic illnesses that are in need of palliative care input, promoting a holistic and individual approach to patient care. Presently Glajchen (2011) refers to patients accessing the ED 'getting stuck in a revolving door' that wastes resources and fails to address the goals of care of the patient. Admissions with a palliative care referral could ease distressing symptoms, educate patients to deal with acute exacerbations of decline in health status, and support patients within the community. The effect may ultimately enhance quality and continuity of care experienced by patients when accessing the ED and reducing some hospital admissions (Glajchen, 2011).

- Palliative Care

The World Health Organisation (WHO) defines palliative care as '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'. Any patient who is suffering from a terminal illness or chronic disease qualifies for

palliative care where the primary goal of care is quality of life (DeVader et. al, 2012). End of life care is an essential part of palliative care where patients health status is dramatically declining and refers to the care given in the last few days or weeks of life.

Palliative care is ideally initiated on diagnosis of a serious illness that requires symptom management, complex decision making, psychosocial and spiritual support involving both patient and relatives (Smith et, al. 2009). This should continue with the patient receiving high quality palliative care throughout the disease process at each entry to the healthcare system (Quest, 2011). The quality of palliative care can be measured in the patients symptom management and family perception of their loved ones death (DeVader, 2012). Whilst palliative care is traditionally associated with those who are dying; it can be offered simultaneously with life prolonging interventions for people living with chronic illness (Grudzen, et. al. 2011). Palliative care has been shown to improve patient's pain and increase quality of life throughout their disease and at the end of life. Optimal quality of life at the end of life allows relatives and family to grieve and avoiding the shock of an unexpected traumatic death. Palliative care has shown to be effective in improving end of life care when that time comes (Milligan, 2009). When patients access ED for support at the end of life it has been documented they encounter problems with their expectations of fundamental care needs (Bailey, 2011).

- A Call for Research

Limited research has been conducted on the subject of palliative and end of life care in the ED; it is an emerging research topic where up until recently the topic had not gained a lot of attention. Studies have looked at clinicians' attitudes toward palliative care in the ED, common barriers associated with the ED and palliative care. This setting is an ideal place to identify patients with unmet palliative care requirements and to put in place a good end of life care plan within the ED. This study looks to explore palliative care interventions that could be implemented in the ED to improve end of life care for patients with terminal and chronic illness.

### **Research Question**

What are views of HCP towards interventions to improve EOLC delivery and their use in the ED?

### **Aims and Objectives**

- To look at palliative care intervention that is in place in emergency departments
- Explore barriers to palliative and end of life care in the ED
- Explore whether the interventions are feasible in the ED setting and whether HCP believe they could improve end of life care
- Looking further whether or how these can be applied to emergencies departments in the UK
- adding to practice and policy to improve end of life care within the emergency department

### **Literature scope**

A literature search was conducted of relevant databases to retrieve any articles or studies that had identified palliative care interventions in the ED to improve end of life care. Using key terms in the databases and an inclusion and exclusion criteria, eight articles were found to be relevant. These articles were then reviewed and the interventions from them developed into a framework to be

used in the focus group. There are four interventions that will be looked at within the focus group; screening and assessment tools, Palliative care champions, education and training within the ED and Improved Documentation in the ED (Appendix 1).

### **Study Design**

Focus Groups will be used to explore this topic as the subject of palliative care in the ED lends itself to focus group as it is not an individual experience. Focus groups have been suggested as a good start when little is known about the area of research (Stewart et. al, 2007). Whilst end of life care has seen an increase in the amount of research conducted, palliative and end of life care in the ED setting is an under researched topic. Most studies and interventions carried out have been in the United States so this focus group is in the exploratory phase looking at the feasibility of implementing interventions into the ED. Focus groups can gain vast amounts of data which provides a detailed insight into the topic, as well as participants being able to qualify responses (Stewart et. al, 2007). The findings from this project will be used to inform a larger feasibility trial to improve end of life care in the Emergency department.

There is a need, like any other research method to maintain rigour throughout the entire process so results can be used to expand knowledge on the subject (Kitzinger, 1995). Limitations of focus groups will be considered throughout the project and strategies put in place to minimise the effect on results. Factors to consider are bias from the researcher, moderator and sample, group dynamics and moderator influence over group and discussions. Credibility, transferability, dependability and conformability of the results will be considered throughout especially in the sampling and analysis of the study.

One of the limitations of conducting focus groups is that the results cannot be generalised to a larger population, however within this study not enough is known about the research topic to be able to generalise to other populations. The aim of this study is to provide meaning and understanding to a previously neglected field, therefore the issue of generalisability does not limit the value of this much needed project.

### **Sample**

Three focus groups will be held in total, one of which will be a pilot study to identify any potential problems prior to the main focus groups thus limiting errors which may affect the results (Stewart et, al. 2007). All results from the focus groups will be used in the analysis, however the pilot group results will be used with caution as the format could have been modified and therefore potential problems may have occurred to alter validity of results but valuable data cannot be excluded.

There is disagreement in the optimal size of a focus group. Decisions are dependent on aim, funding, time and research topic. Sizes vary from five to twelve; the group must be large enough to ensure diversity but small enough that everyone is able to speak (Kitzinger, 1995). Many suggest this is too larger number and that optimal size is 4-5 as this allows each member to fully explain their views and experiences within allotted time (Shaha et, al. 2011). Sample size will therefore be kept at between 6-8 participants thus allowing for over recruitment and accounting for people who do not attend. Participants will be contacted the day before to ensure adequate numbers and attendance.

Purposive sampling will be used whereby participants will be selected based on the topic and this will generate the most productive discussions relevant to this research (Morgan, 1997). The sample should contain HCP from an Emergency department background or palliative care background. The sample should ideally include ED nurses/physicians and palliative care nurses/physicians. Whilst there is divided opinion regarding sampling within focus groups this sample has been chosen, to reflect that participants need to have prior knowledge for meaningful and relevant discussions to take place in the focus group (Cote-Arsenault and Beedy, 1999).

The decision to include nurses and physicians in the same focus group is that the diversity of the participants can enhance the understanding of the topic. In the literature it suggested that nurses were supportive of palliative care yet physicians were more reluctant questioning palliatives care place in the ED (Smith et, al. 2009). . A point to note is the hierarchy within the focus group that more senior HCP present may influence more junior HCP views and opinions however the role of the moderator is to guide equal and fair discussion within the focus group.

Another point to note is that the sample may contain bias towards the research topic due to all HCP being involved in the topic of the research, however the specific specialities of all are required to make the results meaningful. A selected group of participants may not understand the concepts and the workings of both palliative care and the ED which could hinder discussions. Sampling will be carried out systematically to ensure bias is minimised (Morgan, 1997).

The participants will be recruited by contacting managers within the Trust explaining the research and asking to assist in publicising the project. Posters will be put up in the relevant places around the ED department and palliative care offices to recruit relevant participants. If possible attendance at ward meetings or relevant study days would be beneficial to introduce the project and myself which may aid recruitment.

### **Detailed Plan**

Prior to focus groups it is highly recommended to develop an interview guide as this will be useful in directing and enhancing group discussions (Shaha et. al, 2011). A list of questions will be developed to ask at the focus group, these should be in a logically order and progress from general to more specifics but at the same time allowing for development and probing (See Appendix 2). The pilot focus group will help in developing questions and the running of the main focus groups. Starting with a simple neutral question will allow the group to settle into the discussion as well as getting to know others in the group. Natural conversation, ideas and new thoughts will be encouraged throughout leading to diversity of comments and opinions. If questions are well developed and considered they should lead to discussions and led naturally onto the next question, otherwise the moderator can guide and reflect on responses and move to next idea (Cotes-Arsenault and Beedy, 1999). The recommended number of questions is twelve however many studies have found fewer questions are easier to cover in a restricted time frame and allowing everyone to contribute to the discussions and gaining meaningful insight into topic (Stewart et. al, 2007; Kitzinger, 1995) .

Most focus groups last between 1.5-2.5 hours before participants become fatigued and overloaded with information dependant on topic area (Stewart et. al. 2007). A well developed interview guide that has been pilot tested will help the moderator to end the focus group when saturation of data is reached. The moderator will conclude with a closing statement summing up discussions and

clarifying key points. This not only ensures validity of the results but helps to gain understanding of them and starts the first stage of analysis (Shaha et. al, 2011). Throughout the process confidentiality will be ensured, pseudonyms will be used for participants and all will be reminded of the need for confidentiality.

- Recording

Group interactions are an essential feature of a focus group. Audio tapes and an observer will be used to record the focus group and monitor these interactions. An observer is useful for noting the arrangement of the group and the non verbal communication of the group (Curtis, 2007). Technical aspects of recording have been considered and appropriate equipment will be used.

An effective and competent moderator is essential in a successful focus group (Kitzinger, 1994). If they are unknown to participants then the potential for coercion or conflict of interest is avoided. They must gain the trust of the group, conduct session efficiently with confidence and knowledge of the topic being able to guide discussion using probes and open questions remaining neutral at all times. It is useful to have two moderators within a focus group to overcome lulls in discussion or problems with participants, however because smaller groups are being used it is felt two will be too many and may hinder the flow of discussion.

An additional person will be present in the room to act as an observer who is part of the research project. They will start the tape, change tape and take detailed field notes. Field notes have proved to be invaluable during transcription and aid the process of recalling the specifics of the focus group. They should include seating arrangement, the order people speak in aiding voice recognition, non verbal behaviours such as eye contact, posture and gestures and immediate themes that are noticed at the time of the discussions.

### **Analysis**

Analysis of data requires the researcher to go back to purpose of the study in order to address the research goal (Krueger and Casey, 2000). Krueger's (1994) framework will be used to aid data analysis as it provides clear steps to help manage large amounts of data associated with focus groups. Framework is presented in analysis continuum from going back to raw data, descriptive statements and interpretation. A systematic approach will be taken to analysis to enhance rigour of the study making it verifiable and increasing credibility. Process will be clearly documented providing a trail in which other researchers can follow to verify findings, increasing dependability and conformability of results (Raibee, 2004).

Working with my supervisory team or I am keen to publish my findings in high impact journals getting as wider impact on practice as possible. In regard to presenting the findings once complete, academics and clinicians will be given the opportunity to review the findings following completion. This review provides a much needed evidence base. The research findings will help inform the design and implementation of a larger investigating the use of palliative care services in the ED.

## Interventions

### Screening and Assessment tools

#### Two stage rapid screening tool (Glajchen, et, al., 2011)

- Project in US created a rapid standardized two stage screening tool to identify unmet needs among patients 65 years and older seen in the ED.

Stage 1 – patients with specific life limiting conditions (COPD, Severe CHF, Advanced malignancies, dementia and AIDS) with at least moderate functional status limitations were referred to palliative care.

Stage 2 – subgroups with recent losses in Activities of daily living (ADL's), high symptom distress, poor functional status and high level care giver burden were referred to palliative care.

- Both sets of patient were then referred to palliative care and if appropriate had palliative care input with referrals to hospice and support in community if required.
- In conjunction a laminated card of referral criteria was installed and displayed and also a referral hotline was installed, similar to toxicology hotline improves access to information about pain, symptom management and home based services such as hospice.

#### The Rapid Palliative Assessment (ABCD's) (DeVader et, al. 2010)

*(This is to be performed after or at the same time as initial ABCD's in critically ill patients)*

- A) Does the patient have any advance directives in place regarding life sustaining measures? If so what are they?
- B) How can you make the patient feel better? This is symptom management whilst ascertaining how far resuscitation should go.
- C) Are there care givers at the bedside or who can be contacted? If there are take their needs and desires into consideration.
- D) Does the patient have decision making capacity?

#### Palliative care champions/Key worker (Glajchen et, al. 2011; Smith et, al. 2009, Beckstrand et, al. 2012; Grudzen et, al. 2011)

- Training of palliative care champions, these nurses could be trained with a curriculum emphasising communication, palliative care ethics and pain management (Smith et, al. 2009).
- Nursing staff typically are supportive and embrace palliative care, could start to initiate palliative care consults acting as advocate for patient and family.
- Staff in studies embraced palliative care champions felt played active role in ensuring palliative care is appropriate and utilised in patients nearing end of life.
- Links with hospice could enhance their role, nurses from hospice coming to give training or offer advice and palliative care team in hospital meeting with champion and attending meeting in the ED.

#### Documentation (Smith et, al. 2009; Clarke, 2008; Grudzen et, al. 2011)

- Physicians found in the ED they had no documentation about communication with the patient from primary physician about goals of care and were uncertain if these discussions had taken place.
- These discussions around care were then difficult as had no relationship or previous history with the patient or family, further exacerbated by the fact that often the patient was acutely decompensating.
- Improved communication and documentation between outpatient's facilities and primary physicians would improve this.
- Goals of care could be discussed and documented in a way that was clear to and available to the ED.
- Resuscitation status and end of life decisions could be recorded electronically, and flag up if previous do not resuscitate has been in place. May give more indication that discussion have been in place and could guide physicians more in their care.

#### **Education and Training (Beckstrand et, al. 2012; Smith et, al. 2009; Clarke, 2008)**

- Improved communication skills training – discussing best methods to use to resolve conflict and approach sensitive discussion and decisions in end of life care for all HCP.
- Improved symptom management – providing better pain relief for patients, management of symptoms at the end of life.
- Palliative care champions can deliver education and training to other staff.
- Increases consistency and continuity of care addressing educational needs of staff. Provides a multi disciplinary and co-ordinated approach to palliative care in the ED.
- Nurses can find these situations emotionally challenging providing training and support for this as well may be useful.

## Appendix 9- Debrief and Adapted Interview guide from Focus group 1

### Debrief with CB Notes (Pilot Group)

**Attended by;** 2 ED nurses, 2 ED HCA's, 1 ED Sister, 1 ED Charge Nurse/Nurse Practitioner, 1 Student and Palliative Care CNS.

**Definitions** – lots of people said key words such as dignity, comfort, final days, ease suffering and that within the ED it was often sudden.

#### Why people come to the ED?

- An important point covered where nurses stated that often people had made the decision to die at home and then they came in peri-arrest as relatives panicked at home.
- They also brought us the issue of whether this was what the patient wanted and whether bringing them into the ED environment was the right place to bring them?
- people question the validity of the community DNAR and that sometimes the patient's wishes are overridden due to this. Patients have been diverted from hospice to ED due to deterioration.

#### What does EOLC involve in the ED

The same as any other patient; time, space, analgesia, support family, separate room and bereavement care includes information such as leaflets.

#### Barriers

- **Time** – the time to sit with that patient and sort out everything required at the EOL. Time limit of 4 hours and ED ethos of stabilising the patient they do not need to think of long term goals of the patient it is immediate fixes that they require. Ward HCP have a lot more time to care.
- **Communication** – it is essential between HCP and the family and carers.
- **Access to Information** – difficult as no previous history, no access to clinical portal, it is like being a detective trying to find out all you can about a sensitive subject.
- **Patient priority** – patient who is dying and then a patient acutely unwell that has just come in which one do you go to ideally both and spend the time often it is the acutely unwell patient that take priority. It is a busy functioning ED.

#### Interventions

- **Sickle cell information** – they carry a card which has all details on, could have on patients wishes, it is portable. Motorcyclists also have them.
- **Care Pathway** – educate staff about care pathway, could this be available on a computer system so all EOL meds came up when prescribed available in other trust. SCP not used within the ED at present.
- **Resources** – making people aware of the resources within the trust such as the faith centre the chaplaincy.

- **Palliative Care Team** – no referrals for PC team at present ?due to time frame within the ED and PC workload. Would be useful not to have a person based in the ED but as use PC team as a point of reference for the ED staff that they can get advice about difficult situations.

### **Feedback from Handout interventions**

1. **Two stage screening tool** – too many patients terminally ill to refer each one to palliative care some only are coming for relief of symptoms why do they need a referral? The job of ED is to stabilise.
2. **ABCD** – one staff nurse did not like this as already familiar with other ABCD and immediately did not like that. Change the acronym?
3. **SPEED** – different order required in the ED physical, therapeutic, social, psychological and then spiritual.
4. **Palliative Champions** – symptom control more education, ?financially feasible.
5. **Documentation** – everyone agreed on need for universal documentation and need for a care pathway in which nurses could start. Medics needed it to be quick and easy to fill out.
6. **Education and Training** – more training on the use of SCP

### **Development**

There was only one PC nurse present due to their workload and this gave a different focus of the group as often the discussion focussed on the use of the palliative services. From this study it has been decided that the next two focus groups will just be ED HCP and another spate group will be done with just PC nurses. Further studies could look at integration of ED and PC nurses with the right combination of both.

*When the focus group finished I had a conversation with PC CNS regarding how she felt her input contributed to the focus group and she agreed that had she not been there that the results would have been different and that palliative referral may not have been such a talking point. Whilst this was interesting to find out why ED do not refer to palliative care and brought into consideration issues such as time, goals of care for patients at EOL in the ED and the role of the HCP looking after this patient, this is not the objective of the study. We also agreed that she would then know the format of the focus groups and be inclined to prompt answers and discussions. It was agreed a more beneficial way of doing this would be to conduct a separate focus group with just the palliative care nurses and compare the responses from the focus groups.*

During the focus group, handouts were given that show the interventions identified from the literature I believe these require more explanation whilst there is a brief outline on the handout it does not give people a context for them or how they are to be used. Explanations of the intervention may help people understand how they are meant to be used within the ED and in what scenarios.

It would also be useful to have an observer present and cues have been developed for the observer. They should look for any tensions or behavioural changes within the group or towards one another, this is particular important when comparing different HCP and their roles within EOLC but also their attitudes to EOLC and PC.

### **Reflection**

*On reflection this group was really useful to make sure questions were clear and see if people understood them. As I undertook the moderator role I found it difficult not to be leading and ask leading questions in which I knew people would answer in a certain way. This is why an interview guide was developed and used within the focus groups. It was also difficult not to give actual examples such as times, relative's rooms as people tended then to focus on these. Alternative phrases and words have been thought of in these situations and will be used within the next focus group.*

### **Adapted Interview Guide from FG1 Group**

Questions	Total Focus group time 90mins Time for each section approx.
<p>Introduce observer and moderator, names and background. Explain research question and purpose of today to discuss palliative care and end of life in the ED. Remind everyone about confidentiality, there is not a wrong/right answer, want honest answers, opinions, views, remaining professional and confidential if any examples of practice are used.</p>	5mins
<p>Starter for group to interact and set up the focus group</p> <ul style="list-style-type: none"> <li>• Go around introduce everyone and roles and explain what you feel is meant by palliative care and End Of Life Care (EOLC)?</li> <li>• Is there a difference?</li> <li>• Give pre set definitions of palliative care and EOL</li> <li>• Reactions to definition/comments/disagreements</li> </ul> <p><i>This is to set the scene up for participants. Cote-Arsenault and Beedy (1999) suggest that first question should be neutral and simple so everyone can interact and get to know others in the group.</i></p>	10 mins
<p>Patients entering the ED with terminal conditions or chronic illness what are people's experiences of palliative care within the ED? Experiences of EOLC.</p> <ul style="list-style-type: none"> <li>• Experiences good/bad – reflect on why?</li> <li>• Can you identify patients in need of palliative care or at the EOL in the ED? How?</li> <li>• What are the goals of care for patients at the end of life? How do they differ from other patients?</li> <li>• Are there barriers in the ED which prevent palliative care happening? What are they?</li> </ul> <p><i>The literature suggests that there are barriers within the ED that prevent adequate palliative care happening, however all these studies have been mainly conducted in the USA and so cannot directly apply them to the UK due to different healthcare systems. Start to think about EOLC they give as HCP and how it can be improved.</i></p>	20mins
<p>Having thought about barriers to palliative care in the ED, any suggestions to how this could be improved?</p> <ul style="list-style-type: none"> <li>• How can end of life care be improved in the ED?</li> </ul>	20mins
<p>Hand out palliative care interventions that seek to improve end of life care in the ED from barriers identified in literature. Discuss interventions individually in terms of feasibility, problems, impact on care, workload;</p> <ul style="list-style-type: none"> <li>• Assessment tools – Two stage rapid Screening Tool, ABCD &amp; SPEED</li> <li>• Education and Training</li> <li>• Improved Documentation</li> </ul>	(5 mins to read handout)

<ul style="list-style-type: none"> <li>• Palliative Care Champions</li> </ul> <p>Briefly summarise assessment tools in context of how they have been used in the ED and how they might be used.</p> <ul style="list-style-type: none"> <li>• How could you see these being used in practice?</li> <li>• Advantages or disadvantages of using them? Would they work in the ED?</li> <li>• Do you think they could assist PC and EOLC in the ED?</li> </ul>	<p>35mins</p>
<p>Summary of key points and final task to ask participants to write on post it top 3 improvements in the ED for EOLC</p> <ul style="list-style-type: none"> <li>• <i>Could be on the hand out, could be something mentioned or something that you think could improve end of life care</i></li> </ul> <p>Thank everyone for coming and any questions please contact me.</p>	

## Appendix 10 – Debrief and Adapted Interview Guide Focus Group 2

### Debrief with CB Notes

**Attended b:** 5 ED nurses, 1 ED Sister, 2 ED HCA, 1 Student and CB present as an observer.

**Definitions:** Key words used were support not only in when patient is dying but after, pain relief, comfort, family, holistic, respect, patient wishes and comfort.

#### Experiences

- Only negative experiences were discussed; patients brought in from hospice as they did not know what was causing drowsiness and people coming in for symptom control who later died in the ED.
- People coming in from community when DNAR have been put in place and patients documentation has been lost
- patient did not want to be admitted to hospital in the event of acute deterioration and in some cases resuscitation had taken place when patient did not want it to.

#### Barriers

- **ED as a place for EOL care**

Many focussed on the appropriateness of the setting to provide EOL care. It is noisy, bright, no privacy. When people come in they try to resuscitate them and make them feel better before they decide that patient should be for TLC. Described as a 'stop gap', unable to provide certain things e.g. overnight stays, accommodate relatives.

There was also discussion as to ED main aim of "saving lives" that time is spent trying to "save" someone that will die due to lack of communication and documentation. Nurses present that this is in the case of doctors that work in ED are of the "saving lives" mind set and are taught to save lives and looking at the physical aspect of patients; often nurses advocate standing back and examining patient as a whole and what will interventions achieve.

- **Time**

Was a huge factor throughout the focus group that people felt they did not have enough time to spend with the patient and family in this difficult time. Wanted to be able to provide reassurance but difficult when have other patients and priorities coming in. Often student and HCA's take this comfort role and do this when perhaps they should not be expected to.

- **Community**

The community setting as a whole was discussed a lot in terms of validity of the DNAR, lack of support in community. An interesting comment was that you will never stop some admissions as people are not prepared for the death of a loved one and the implications this comes with. The groups also considered what roles GP and DN's played in the admission of these patients to the ED and what they could do help.

Nurses within the group also felt that on the wards they had good links with PC and community and PC and community within themselves had good links but the ED was missed and left out of this.

- **Care/Resources to provide care**

ED gets so many patients coming in with various terminal illnesses and chronic conditions – need expertise in all of these. If someone wanted to go home who had COPD unsure of who to call palliative care? COPD CNS? Many did not know if palliative care team came down to ED or if they did an on-call. Did not know where the faith centre was or if it was appropriate to send people there.

**Interventions:**

- **Fast track care pathway** – much like NOF pathway within an hour of confirmed NOF have to do certain things. But within this hour could optimise patient care.
- **Trigger system/Flagging system** – PC and community matron aware that patient is in ED similar to the oncology pathway. Oncology CNS come and see the patient within certain time of them being admitted if this could happen with palliative patients. With this intervention people suggested an electronic system that it would show up if they had been on a supportive pathway or known to hospices etc that it could flag up.
- **Community support** – provide support in the community educating families on symptoms and what to expect. Give contact details.
- **Palliative care on-call** – to be used as a point of reference if nurses are unsure of how to proceed with patients or how to get them home, what they require are home and what is available in the community. They wanted them to come and sit with the patient and provide comfort.
- **Education** – general education, who to contact when, knowing what resources are available, hospice at home is available which no one discussed, having hospices number on the wall so can get in touch. Resources are going to be put up in the relative's room. Analgesic education. Were unsure of who the link nurses were.

**Feedback from Handout interventions**

7. **Two stage screening tool** – on the tool the age is specified as 65 however people suggested as it is a large ED and hospital it accepts more patients and that there should be no age limit.
8. **ABCD** – Liked this intervention as it immediately addresses needs of patient and involves basic assessment which would then make them look more in depth. Many suggested a flow chart as the questions if the answer was NO or YES what then action do you take.

*Suggested it could be linked to first tool in some manner to refer patients and can follow flow chart. Decisions made by junior staff are influenced by senior staff an flow chart may be able to help junior staff make more decisions regarding care. An interesting point made was that care should not be made into a checklist/tick chart.*

9. **SPEED** – different order need to address physical and therapeutic especially medical staff more interested in physical aspects. In ED want a quick fix otherwise turns into ward care.
10. **Palliative Champions** – would work well need to consider more education

11. **Documentation** – more resources would be useful. Care pathway and fluidity of care from community to hospital
12. **Education and Training** – There were things mentioned that could not be done in the ED, which in practical terms could be. Education on what is available to them, resources, community resources and services.

### Development

A de brief was carried out with CB after focus group where main points were discussed and what worked well. A development will be whilst interventions were going to be explained the group was quite vocal and initial thoughts on the interventions wanted to be captured however CB and myself feel the group would still benefit from them being explained further.

An additional question will be added to further research which is what elements would you include on a similar model or within an intervention? What is important when designing a tool for use in the ED? Whilst the background is important, some of it has been covered in other studies and within this study we want to find out what interventions could improve EOL care and what would be useful within the ED.

At the start of the focus group participants are asked about experiences of EOL care in the ED, so far these have all been negative. In the next study we would like to probe further to see whether any examples of good practice can be obtained to see what works and why? This information can then be used as an example of what we want to achieve and the process can be analysed as to what was different to the bad experiences.

### Reflection

*I found this focus group were a lot more vocal than the previous and required me to probe less to obtain answers to the questions. There was also a lot more discussion with people suggesting ideas and then evaluating them within the focus group. I felt that I had less influence over the group and had to contribute less.*

*CB observed that I write notes quite a lot throughout the group and it could be beneficial for just the observer to write the key notes down as then the moderator will be more involved in the focus group and discussion can flow easier with probes being used more frequently to explore certain ideas.*

### Adapted Interview Guide

Questions	Total Focus group time 90mins Time for each section approx.
Introduce observer and moderator, names and background. Explain research question and purpose of today to discuss palliative care and end of life in the ED. Remind everyone about confidentiality, there is not a wrong/right answer, want honest answers, opinions, views, remaining professional and confidential if any examples of practice are used.	5mins
Starter for group to interact and set up the focus group <ul style="list-style-type: none"> <li>• Go around introduce everyone and roles and explain what you feel is</li> </ul>	

<p>meant by palliative care and End Of Life Care (EOLC)?</p> <ul style="list-style-type: none"> <li>• Is there a difference?</li> <li>• Give pre set definitions of palliative care and EOL</li> <li>• Reactions to definition/comments/disagreements</li> </ul> <p><i>This is to set the scene up for participants. Cote-Arsenault and Beedy (1999) suggest that first question should be neutral and simple so everyone can interact and get to know others in the group.</i></p>	10 mins
<p>Patients entering the ED with terminal conditions or chronic illness what are people's experiences of palliative care within the ED? Experiences of EOLC.</p> <ul style="list-style-type: none"> <li>• Experiences good/bad – reflect on why?</li> <li>• Can you identify patients in need of palliative care or at the EOL in the ED? How?</li> <li>• What are the goals of care for patients at the end of life? How do they differ from other patients?</li> <li>• Are there barriers in the ED which prevent palliative care happening? What are they?</li> </ul> <p><i>The literature suggests that there are barriers within the ED that prevent adequate palliative care happening, however all these studies have been mainly conducted in the USA and so cannot directly apply them to the UK due to different healthcare systems. Start to think about EOLC they give as HCP and how it can be improved.</i></p>	20mins
<p>Having thought about barriers to palliative care in the ED, any suggestions to how this could be improved?</p> <ul style="list-style-type: none"> <li>• How can end of life care be improved in the ED?</li> </ul>	20mins
<p>Hand out palliative care interventions that seek to improve end of life care in the ED from barriers identified in literature. Discuss interventions individually in terms of feasibility, problems, impact on care, workload;</p> <ul style="list-style-type: none"> <li>• Assessment tools – Two stage rapid Screening Tool, ABCD &amp; SPEED</li> <li>• Education and Training</li> <li>• Improved Documentation</li> <li>• Palliative Care Champions</li> </ul> <p>Briefly summarise assessment tools in context of how they have been used in the ED and how they might be used.</p> <ul style="list-style-type: none"> <li>• How could you see these being used in practice?</li> <li>• Advantages or disadvantages of using them? Would they work in the ED?</li> <li>• Do you think they could assist PC and EOLC in the ED?</li> <li>• What elements would you use or include in a similar tool?</li> <li>• What is essential in a tool or intervention for ED surrounding EOLC and PC?</li> </ul>	<p>(5 mins to read handout)</p> <p>35mins</p>
<p>Summary of key points and final task to ask participants to write on post it top 3 improvements in the ED for EOLC</p> <ul style="list-style-type: none"> <li>• <i>Could be on the hand out, could be something mentioned or something that you think could improve end of life care</i></li> </ul> <p>Thank everyone for coming and any questions please contact me.</p>	

## Appendix 11 – Debrief and Adapted Interview guide for Focus Group 3

### Debrief with NE

**Attendance;** 2 ED nurses, 1 HCA, 1 ED sister and NE observing

**Definitions:** key words were used comfort, pain free, dignified

Tracey disagreed with the EOLC definition as she suggested that it is not just in the last days of life but is a boarder term for PC and intertwined with PC throughout.

### Experiences

- Overall the experiences were negative with both staff nurses having negative experiences which they identified came down to communication and the setting not being appropriate. Good experiences were mentioned that patients had received good end of life care and aspects that made this good was the continuous nature of the care and that it was smooth and moved very quickly.
- Specific examples were used in the media such as the LCP and an MP who brought their husband to the ED and received poor care. When explaining these they justified why it had such bad press and due to time constraints on the ED.
- One participant kept on referring to other patients not those with terminal and chronic illnesses such as burns and neuro patients that come to the ED at the end of life, whilst they were good examples it was not specific to the patient group we are looking at.

### Barriers

- **ED design** – lacks privacy and comfort for both patient and relatives
- **Time/Prioritisation** – one of staff nurses compared to the ward where time did not have as much effect or you could spend more time with people and catch up as it were.
- **Lack of Staff**
- **Community** – lack of information from community and support in the community

### Interventions

- **Separate Room** – place to take the family and patient, separately staffed and give support.
- **On-call team** – a team to be available 24/7 for support in the ED to support the family and provide that link for family to help them understand what has happened and next steps. The group were not aware that you could bleep PC or refer to PC from the ED. Useful to have someone to provide advice and support when dealing with difficult situations. An interesting point brought up was that even though you as the nurse have admitted that patient and been there from the start would you want another HCP to come and take over care?
- **Education in the community** – families, GP, ambulance
- **LCP** – a varied discussion as to appropriate care pathways for patients, whilst two nurses were severely against the pathway the other had seen in work in practice and worked really well! One of participants said that the checklists were already in place were adequate for the needs of the ED, no more paperwork was needed. It is not an appropriate place for this kind of assessment to be taking place.

## Feedback from Handout interventions

1. **Two stage screening tool** – Do not get patients that come in without palliative input in the community. How would you run it? Financial aspect.
2. **ABCD** – Good. Focussed on what was important to the patient, pain is a priority.
3. **SPEED** – Good feedback as it was a tool for patients and nurses that addressed what patients needed and how nurses could help.
4. **Palliative Champions** – They liked it and have link nurses, could not identify them though. Not aware of the reintroduction of the priority of care that link nurses are doing.
5. **Documentation** – an EOL pathway would be useful but questioned its usefulness in the ED lead back to the LCP and peoples view that it is inappropriate. Care rounds at present some believed covered all that needed to be addressed in terms of care and did not want more paperwork that would make it into a tick chart rather than just providing basic care.
6. **Education and Training** – education of families on what to expect when at home and maybe the paramedics to say this is normal do you want to go hospital and provide reassurance at home. Education on pathway.

It was interesting as group did not really focus on the interventions given on the handout but were a lot more focussed on the care pathways especially controversy over the LCP; whether it was appropriate at the end of life. Some of the group seemed quite hostile towards more paperwork and interventions being put in place that they did enough and it was not a ward where care is very different. All interventions were more focussed outside of the ED rather than within the ED. Education was for the services in the community and a team coming into the ED to support EOL patient.

## Reflection

*I felt this was a much more difficult group as to start off with it was smaller and had quieter members of the group however I feel the dynamics of the group overall were really different to previous. Two members of the group were quite vocal and one with very strong opinions who made very bold statements regarding interventions and care – they obviously had very strong views about what ED should be. They also turned the questions around to ask me what I thought which I found difficult to answer impartially.*

*A expert was present the trusts led on EOL care which was great to get her opinions however she remained really quiet and at the end summarised nicely some misconceptions that were talked about during the focus group. I think after this the more dominant characters recognised this and were more careful as to their responses. Overall I found this group more difficult to moderate as a lot of direction had to be given.*

## Development

The next group will be the PC nurses where the questions will be adjusted slightly due to their role, experiences and the fact that they do not work directly within the ED. Questions will be asked about some of the information obtained in these focus groups such as the referral process from the ED to PC, education and training that could be achieved in the ED and why they are not accessed by the ED. Not seen so much as a focus group but a key informant meeting. More information needs to be





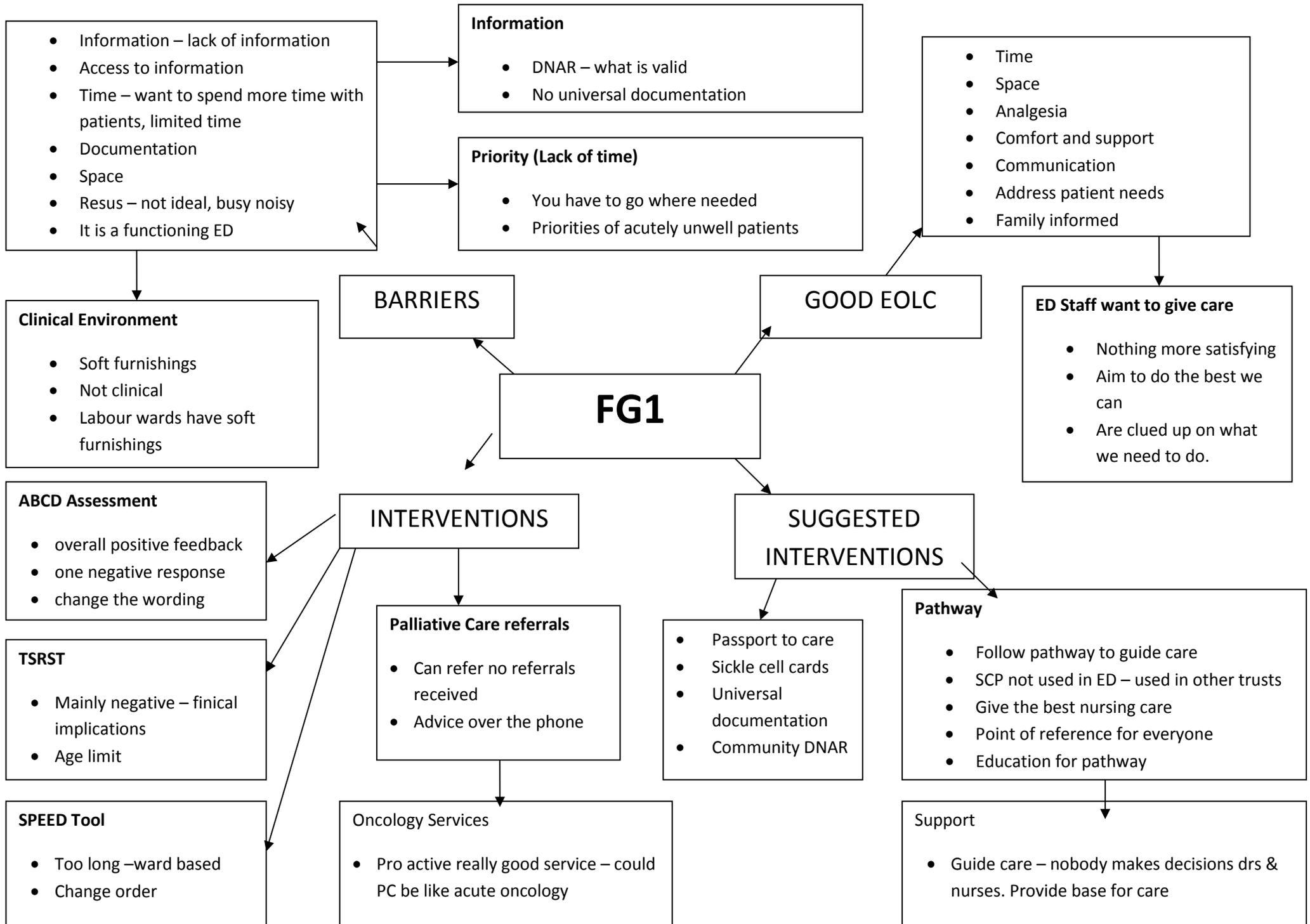
## Appendix 13 – Basic Codes and Themes

Codes/Basic Themes	Themes/Organising Themes	Overarching Themes/Global Themes
<p>Nurses want to do it themselves</p> <p>Negatives experiences</p> <p>Inappropriate admissions</p> <p>Pain free</p> <p>Symptom relief</p> <p>Analgesia</p> <p>Comfort/making patient comfortable</p> <p>Separate area for palliative patients</p> <p>On call team for palliative patients</p> <p>Be there for patients and family</p> <p>Appropriate place</p> <p>Saving lives</p> <p>Quick fix</p> <p>Stop gap</p> <p>Accident and emergency</p> <p>Stabilise</p> <p>Quick process</p> <p>Physical aspects</p> <p>Dignity</p> <p>EOLC</p> <p>Peace and Quiet/peaceful</p> <p>Good death</p>	<ul style="list-style-type: none"> <li>• Experiences of EOLC</li> <li>• A Good death</li> <li>• Basic function of the ED</li> <li>• EOLC satisfying</li> </ul>	<p>Death in the ED</p>
<p>Lack of Privacy</p> <p>Not accommodating</p> <p>Cubicles not private</p> <p>ED not right place for EOLC</p> <p>Personal experience ED EOLC</p> <p>Busy environment</p> <p>Machines &amp; shouting</p> <p>Trauma alerts</p> <p>Busy environment</p> <p>Chaotic Environment</p> <p>Quiet room/relatives room not appropriate</p> <p>Resus Environment</p> <p>Negatives of the place</p> <p>Mum and baby room</p> <p>Ideal environment for EOLC</p> <p>Clinical environment</p> <p>Limited Space</p> <p>Environment not appropriate</p> <p>Clinical environment</p>	<p>Environment</p> <ul style="list-style-type: none"> <li>• Clinical</li> <li>• Lack of space</li> <li>• Resus environment</li> </ul>	<p>Barriers to EOLC in the ED</p>
<p>Community DNAR not valid enough</p>	<p>Lack of Information and</p>	

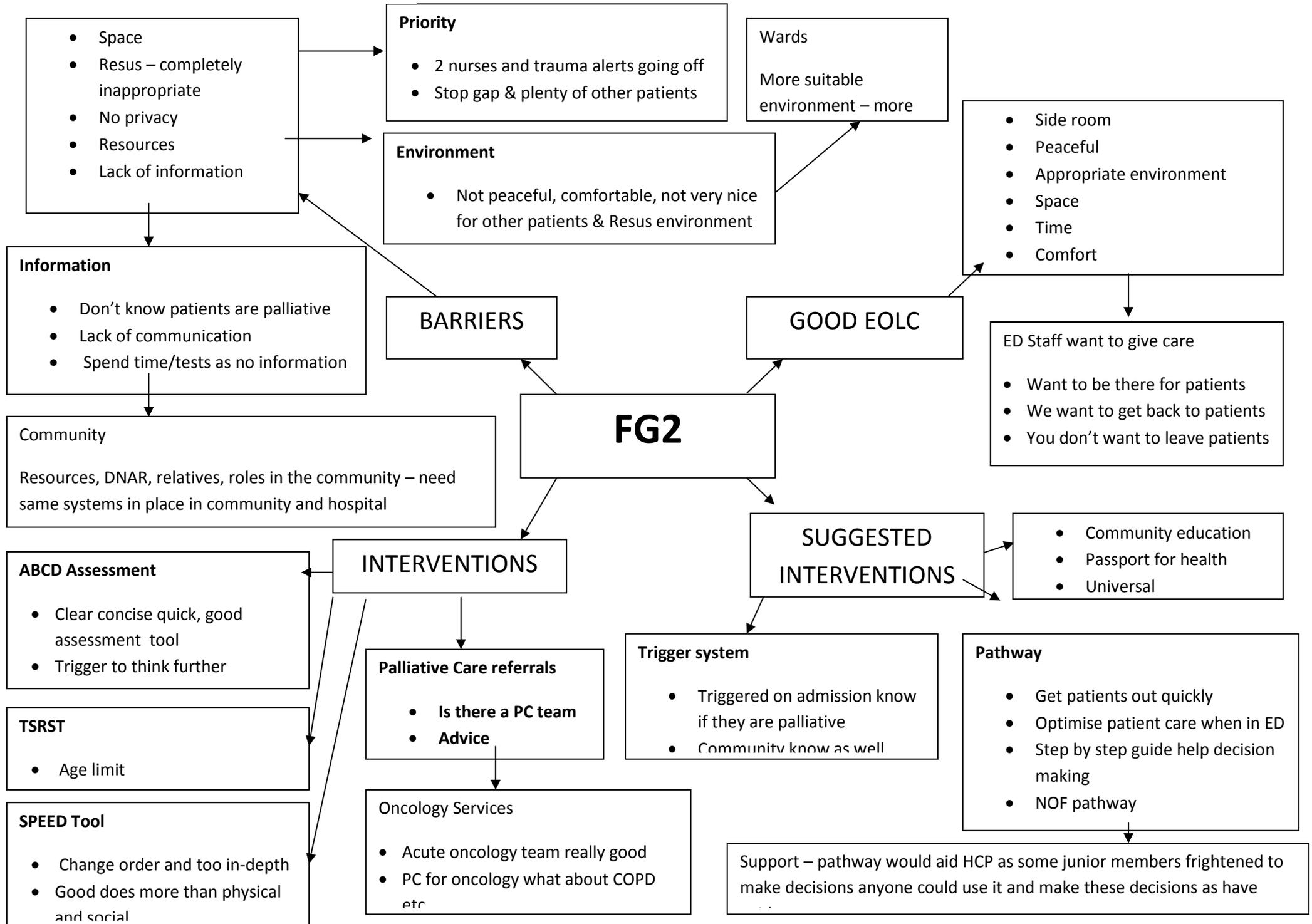
Paperwork – invalid documentation	<p>Communication</p> <ul style="list-style-type: none"> <li>• Community</li> <li>• Lack of access to information</li> </ul>	
You don't have any information		
Lack of access in ED		
Documentation not filled in		
Limited access to information		
Community		
Patients wishes		
Decisions made in community not upheld		
Lost documentation		
Inappropriate resuscitation		
Expectations	<p>Priority and Time</p> <ul style="list-style-type: none"> <li>• Time</li> <li>• Being there</li> <li>• Acutely sick vs. EOL</li> </ul>	
Lack of time with patients		
Different pressures		
Trauma alerts		
Sick/critical patients		
Time constraints		
Reassess priorities		
Spread yourself thinly		
Competing demands		
Prioritise patients		
Other patients in ED		
Needed all the time		
Want to spend time with patient		
Lack of time to assess		
Acutely sick vs. EOLC	<ul style="list-style-type: none"> <li>• Pathway</li> <li>• Universal documentation</li> <li>• Education</li> </ul> <p>Suggested interventions to improve EOLC</p>	
Education in community		
Managing expectations		
Education patients		
Education relatives		
Education ambulance crews		
Information more accessible		
Education on resources		
Trigger system		
Pathway		
Oncology		
Palliative care		
Liverpool Care pathway/supportive care pathway		
Pathway optimise care		
Senior support		
Guidelines		
Consistent care		
Point of reference		
Pathway to get patients out of ED		
Pathway similar to #NOF		
Universal documentation		

Uphold patient wishes		
Patient preferences		
EOLC care plans		
Sickle cell documentation		
Passport to care – chronic conditions		
Positive ABCD	<ul style="list-style-type: none"> <li>• ABCD assessment</li> <li>• RTSST</li> <li>• SPEED Tool</li> <li>• PC champions</li> </ul>	Established Interventions
Negative ABCD		
Positive RTTST		
Negative RTTST		
Positive SPEED tool		
Negative SPEED tool		
PC champions – good idea		
Link nurses		
PC team		
PC referrals		

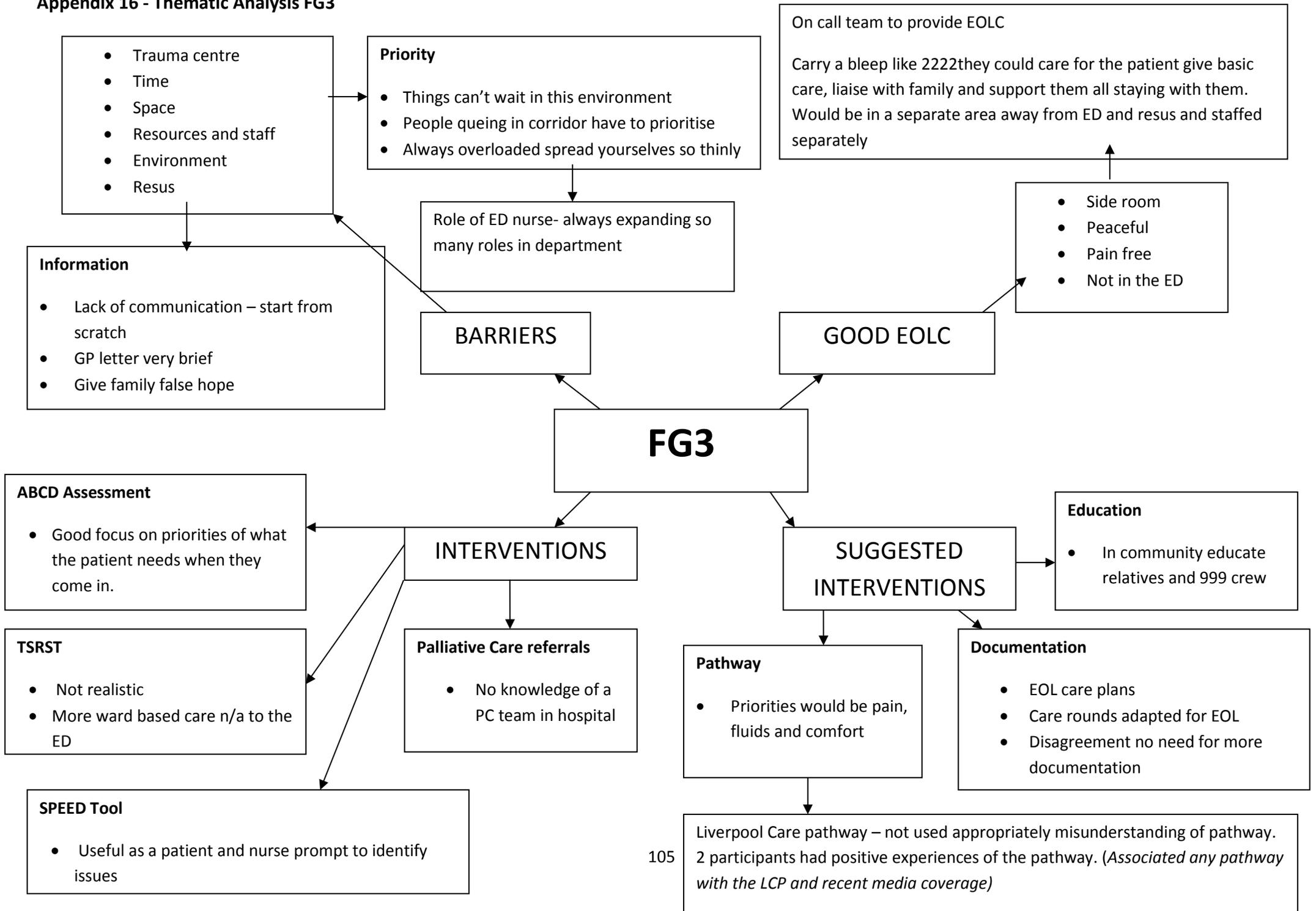
**Appendix 14 - FG1 Thematic Network Analysis**



## Appendix 15– FG2 Thematic Network Analysis



## Appendix 16 - Thematic Analysis FG3



## Appendix 17 - Death in the ED Quotes from Focus group

### Experiences

Pts at the EOL are the same as any other get them to the most appropriate area and if you can a SR where it is quieter ensuring family support which is difficult in this environment as it is always changing' (ED RN FG1).

Everyone deserves to die with dignity don't they it is just a shame it can't happen in the ED (ED RN FG2).

'EOLC a lot of the times there's been care plans set up in the community that have been palliative for a while and then it does come down to it and you do get to the last stage of life and relatives panic call 999 and a lot of the time through DNAR in community they are brought to us in the peri- arrest state' (ED SIS FG1)

They have even been brought on route to hospices here, haven't they when their condition has changed. (ED RN FG1)

'We should respect all wishes, thoughts and feelings and I find that can be really difficult in the A&E department and some things can't be uphold that people want in the community because they come in to an A&E department and it's not really the best suitable place for them' (ED RN FG2)

'I know I had one quite recently actually what was a bit of a bad experience, we had a patient brought in that was EOL, PC in a hospice and then she was basically just last few days of her life and they actually called an ambulance for her to be brought to hospital because they didn't know what was causing her to die even though it had already been discussed and I think the nurse...got a bit panicked and we just thought it was very...not very nice or appropriate' (FG2 ED RN)

'We had similar situation who they brought in...was...EOL...can't remember exactly what the circumstances were she essentially had become quite drowsy and unresponsive and they established that she had had a stroke but she was not for resus, she was palliative had a PC team it was all in place, similar situation plan and they brought her in because she wasn't responding, for us to be like oh there's nothing we are going to do for her, there is no treatment we can offer because of the circumstances' (ED RN FG2)

I have only been here a few months but probably the one that sticks out is the one that the patient shouldn't have even been sent here er...and I find that happens a lot, he wasn't for resus he deteriorated I can't remember what he got now...errr..I think it was bowel ca and erm...he deteriorated and a locum GP had sent him in and you think for what? (ED RN FG3)

### A Good Death

'Giving patients time, space, analgesia so they're not in any pain, addressing family needs' (ED RN FG1)

'Its all about communication, keeping the family informed' (ED RN FG1).

'Get patients to a comfortable bed; keep them pain free and in a SR' (ED SIS FG3).

'Quiet and comfortable' (ED RN FG3)

'Space and Time' (ED RN FG1)

'It is about alleviating symptoms at the EOL or as pts are progressively in their disease process and supporting family and friends and about looking at where a patient would want to be at the EOL' (PC CNS PC Meeting (PCM)

'Making sure that the pt is as comfortable as can be and making as far as you can a dignified death' (HCA FG1)

"It is all about dignity in care and respect, just making like, they are comfortable and support the family" (ED RN FG1)

'PC and EOL care are things that are very personal to the patient and the patient's family, it should be patient focussed, very holistic and very individual' (ED RN FG2)

### **Good Death Continued...**

'Its all about supporting the patient and family' (ED RN FG2)

'Giving the ultimate pain free dignified death that you could give' (FG3 ED RN)

'PC for me is about trying to do symptom control and make sure the patients are comfortable' (EOL CORD FG3)

### **Basic Function of the ED**

'Now the thing is with ED it's a very fast pace it's a very fast area' (ED RN FG3)

'Because of the business of resus, now we'd like to help them and do as much as we can however it's still a busy resus' (ED RN FG3)

'Need to remember it is a functioning ED' (ED CN FG2)

'Its all about the quick fix, doesn't matter about the long term implications, we stabilise and ship them out, thats what we do' (ED CN FG2)

'There is no way in an A&E department we can accommodate that, all we can do is just make it a quick process like a stop gap before they go somewhere that is suitable... (ED RN FG3)

The fact we are a trauma centre, more trauma's came to us we can't stop that and say we just need to deal with these patients' (ED RN FG1).

'It's about saving lives' (ED RN FG2)

'I think because they are medics that are A&E doctors they're here to save people's lives they're so tunnelled visioned that this person has got this and I'm going to save them and they need some time to take a step back' (ED SIS FG2)

'We'd like everything to be nice and quiet for them and relaxed for them tea and coffee set out for them, a box of tissues you know explained to them what's happened and be there for them but then but we're like but yeah.., but also you've got trauma alerts coming' (ED RN FG3)

'More focus towards life saving end of that because obviously we have to save lives as much as we can and when we can you know' (FG3 ED RN)

### **Staff want to be there**

'From a staffing point of view we desperately want to get back to them and if we know they are palliative then we will try to get back to them as much as possible' (ED RN FG2)

'You want to be sat with that patient especially if they have no relatives you don't want to leave but sometimes you don't have a choice' (ED RN FG2)

"There is nothing more...satisfying than to be able to give someone good palliative or EOL care and making the best you can for that person and their family it is the most satisfying thing you can do and a lot of the time you think...I personally get quite caught up in trying to make sure that I wouldn't think to involve others" (FG1 ED Sister).

"I think to be fair in ED palliative or non palliative it doesn't make a lot of difference in terms of if somebody is in pain you want address the pain and if somebody's frightened you want to try and reassure them in terms of what we physically do we would want to do that for everybody' (FG1 ED RN)

'The fact that we are nurses we are in this for the right reasons that we want to be and looking after our patients, talking to them but sometimes it's difficult to get your head round the curtains' (FG3 ED RN)

### **Oncall Team/Area for patients at the EOL**

“Just someone to carry a bleep and then they would be trained that they then go to that area and familiarise themselves with that patient and then they would be until that patient passed away they would be you know there and for them to arrange...a peaceful area to liaise with the family so literally like they would be...you know like you’ve got your resus team that has the badges and be like calling like whatever like EOL team to go to...they would have an designated area and go there the patient would be already there waiting for them and introduce themselves to the family and I am going to be looking after your mum, son, father. They would obviously be qualified and doing all the appropriate stuff and liaising with the appropriate people like priests and things like that, their purpose would be to comfort the family, comfort the patient, make sure you’ve got the right analgesia and basically making EOL that much more better, they become like a friend of the family” (FG3 ED RN).

‘Well yeah that’s something we could do with then an on-call team’ (FG3 ED RN)

“Can I just ask if you have someone come in like a major trauma and personally you’re involved in their resus and everything would you really want to pull in someone else in from outside when you have connected with that family within that really traumatic journey?” (FG3 EOLCC)

‘I wouldn’t want a member of my family still in that area where it’s all going bizzuck you know what I mean? I couldn’t get my thoughts together you know so I think having somebody there...I think it’s the personalities of that person that’s introducing themselves cos you can say we are moving them to CDU after that’s sort of point, but we are still handing them over to a CDU member of staff and then...thats...that CDU staff to build a rapport with that family and when they came into us as part of this stage of the trauma we are still building up a rapport with all be it we do it within 4 hours we are still building a rapport with that family and we are telling them exactly what is going on at each stage and alright we built up that..that..erm...relationship with them but no more than what I have or CDU staff would when we take them round there...or..trauma ward wherever they go...I see your point but there’s the other side as well’ (FG3 ED RN)

## Appendix 18 - Barriers to effective End of Life Care in the ED – Environment

### Environment

“I think everyone deserves to die with dignity don’t they? It is just unfortunate this can’t happen sometimes in the ED” (ED RN 4FG2)

“I don’t think the ED is the right place for EOLC” (ED RN FG3)

“I think the difficulty we have which I know has already been spoken about it is the place...I think I think that’s a big barrier for us” (ED RN FG1)

‘Because you can’t change the environment you are in’ (HCA FG1)

‘There’s not a suitable area....is there?’ (ED RN FG2)

‘I don’t think the ED is the right place for the EOL and I think we need to find something quickly and I think there needs to be something in a policy where if you get to that stage we move them...quickly to a peaceful place’ (ED RN FG3)

‘I don’t think ED is the right place for it to be fair...and like there needs to be a policy when they came in that they are moved’ (ED RN FG3)

‘We’re really rammed your still taking patients in and its happening in a bay or in resus where it’s just pandemonium that’s just not right’ (ED RN FG3)

‘one of the priorities so they can die hopefully in a side room with their families not in a busy A&E department’ (ED SIS FG3).

### Clinical Environment

‘I know on labour wards they have a special room if they have a mum and baby...if the baby has passed away, that mum and partner can go into with a double bed, that have time, peace and quiet and soft furnishing it’s not clinical, and with all the money and time and space in the world it would be lovely to have a room like that’ (ED SIS FG1)

‘Where you could move your patient to if it was imminent, say if it was in the hour, for example erm...say going to a ward. Somewhere a little bit more homely I suppose’ (ED SIS FG1)

‘I think in a hospital it’s clinical isn’t it? That’s why people opt to be at home it’s their own surroundings it’s their own stuff erm...even though it was clinical the patient was around family the family was around the family it was really good because they were all around she got to see them and they got to be with her even though it is a clinical environment’ (ED RN FG3).

### Space

There is no area patients can go to be on their own, we want them to go into a SR but sometimes it doesn’t happen’ (ED RN FG2).

‘It is not very nice for the patients next door they can hear what’s being said and the family grieving they have to lie there any listen to that’ (ED RN FG2)

‘We can’t build a suitable area, we can’t do one on one nursing, we don’t even have cups to provide tea or food there is no way we can accommodate that in the ED’ (ED RN FG2)

### Space Continued...

'I think quite often what you said going back to like being the person next door and hearing to it all, quite often they think then think the same thing going to happen to me because of the area their in, and it's that whole like you said having time to reassure everyone' (ED RN FG2)

'The same thing it's like a cubicle out there, the only thing that separates that cubicle form the rest of the department is a curtain...you know it's not exactly an ideal place' (ED RN FG3)

'It's just a cubicle, it's an oblong room with a with a curtain in front of it and people racing backwards and forwards to get drugs, talking about other patients its just like your thinking oh boy' (ED RN FG3).

"I do always feel quite sorry for the families that even if we move them to the quiet room and things like that you know, the family can still here all the noise from the resus area but then again we are also trying to *save lives of people that have had traumatic injuries*"(FG3 ED RN 2).

'We do struggle with space for families more so even if you have people diagnosed with terminal illness quite often they will be put in cubicles and not in resus just because they are palliative' (FG3 HCA)

### Resuscitation Department (Resus)

'It's a horrible environment in the resus room. It is so loud there is always a trauma alert going on, there is always shouting and there's noise, it is very difficult to give someone a dignified and peaceful time with their family...and that's the last thing they are going to remember' (ED SIS FG1)

'I have looked after somebody where they are in the last hour in a cubicle and we took them out of resus because it was so busy and noisy in there and because it was so imminent we didn't want to move them we thought that they might die on route to erm...and thats just not right is it?' (ED RN FG1).

'we do have people that pass away in resus which to me is completely inappropriate because of the noise, you've got trauma alerts going on... you've just...just the whole environment is no privacy there for the families and personally I wouldn't like it for my own families' (ED RN FG2)

'It's not really quiet, its not very comfortable, you're on trolleys that aren't very wide they are not very accommodating, you've got three curtains around you, with not very much space for all your family to come and sit down' (ED RN FG2)

'It's just not very dignified...and it's certainly not peaceful enough for them to feel comfortable' (ED RN FG2)

'In resus you can have a COPD as you say at the EOL stage and then we've got multiple traumas coming in, that family is not being allowed to sort of get their thoughts together cos of people shouting in there trying to save lives as well I think really many would choose the design or the way we should of had a separate area we could move them to that's run by a smaller'' (ED RN FG3)

'I wouldn't want my family member in that area' (ED RN FG3)

There is a quiet room by resus I don't agree with where it is there is only a door that separates it and they can still hear everything going on; machines, shouting, its not the right environment' (ED RN FG3).

## Appendix 19 - Barriers to effective End of Life Care – Lack of Communication and Documentation

### Community – DNAR/Community Documentation

'People are not sure what is legally binding or what stands? When are they legally binding from the community' (FG1 ED RN)

'I think the community DNAR should be more transferable, it is ridiculous that paperwork in the community and decisions are made and then patients come into hospital and there has been a delay in the DNAR and patients have been inappropriately resuscitated' (ED RN FG2)

'Community DNAR not being enforced' (ED RN FG2)

'Patients have been admitted because they couldn't find the documentation' (ED RN FG2)

'It is ridiculous people are admitted because they can't find the paperwork' (ED RN FG2)

'Care plans are set up in the community and you get to the last stages of life and relatives panic and even though they are DNAR in the community they are brought in ED in a peri-arrest state' (FG1 ED SIS)

'They divert [one route in the ambulance] as not aware of the validity of the DNAR, they are not specific enough They are in a hard place as if they carry on they could be fired or lose their registration for not acting appropriately so they will bring the patient here rather than letting pts dying in the back of the truck' (FG1 ED CN)

'There is not a universal document that will go anywhere we can follow' (FG 1 ED RN 2).

### Lack of Access to information

'We lack access in the ED' (ED CN FG2)

'If you has information beforehand that maybe an indicator for getting us [PC] involved' (PC CNS FG2)

'The times when you spend an hour trying to save someone's life when they are dying because you don't have the relevant information or the paperwork goes missing' (ED RN FG2)

'If patients come in with a family member or nurse that knows exactly what is going on that is completely up-to-date or if documentation was present to say this is my condition but so we are aware of diagnosis we will always attempt to resuscitate if appropriate' (ED SIS FG 2)

'Lack of communication comes into it as well when a patient comes in and you don't know anything about them you are starting from scratch' (ED SIS FG3)

'If the GP sends a letter in with them it is so brief, what they have come in with not their entire history' (ED RN FG3).

"In the ED we don't have the luxury of time, like you do on the ward, ward based care can plan care over a twenty four hour period, we have a very short amount of time to make our initial assessment and decide what is happening with this person...are they going home, are they going to a ward, are they going to the mortuary? And those are the three outcomes from ED point of view and you have a very limited amount of time to make that decision. The problem we have is we have four hours to find out everything we can about that person and....we rely a lot on what has been gathered by the ambulance service before they get here and information the doctor knows about or relatives have *imparted information that they forget to tell you, staff here...a lot of it is bits and pieces coming together*" (ED CN FG2).

### **Lack of Access Continued...**

'So you might get patients who come in and we start doing loads of tests and things on them because we don't know that they're actually dying at that point and the relatives hope are actually built up because we're being pro-active in our treatment and we have to tell them the same thing again and upset them'' (FG3 EOLCC).

"You don't always know they are palliative unless you've got a relative that's told you or they've come from the home and they've told you...it might be an hour till you've found out'' (FG2 ED RN).

'I think it's the lack of communication as well, that you get from when the patient comes in you don't know anything about them and your starting from scratch which is difficult' (EOLCC FG3).

'Yeah, so it's like we said it's communication and different interpretation [of handover or patients condition]' (FG3 ED RN).

'You would go on the information that we have got and...ring GP, involve families, involve the patient and It gets like a detective after a while' (FG1 ED SIS)

### **Patient's Wishes**

'Let's be honest...by the time the patient comes to you their probably not in a fit state, whether they're not compos mentis enough to express their wishes' (FG2 Line ED SIS)

'They have been bought in on route to hospices when they're conditions has changed which is a shame as it is not the patients wish and generally they will die here' (FG2 ED RN).

'Patient had been sent by a locum GP that shouldn't of been as he had deteriorated and should of been at home as that was his chosen place to die, there is the trauma of being bought in and all the messing around in resus when he had chosen to die at home' (FG3 ED RN).

'It wasn't appropriate when she had requested especially when she had specifically requested when she was awake and completely able that she did not want to die in hospital' (FG2 Line 70 ED RN 2).

## Appendix 20 - Barriers to effective EOLC – Assessing Priority and Time

### Lack of Time

'It is not just at the EOL, quite a lot of the time you have got someone that is sick and you want to spend more time with them, or they have complex needs...you can't because you have spilt yourself in about ten different directions...you just can't do it... It is really difficult' (FG1 ED SIS).

'It doesn't always stop it from happening sometimes it can happen, a lot of the time for me personally it is time, you just don't have the time to spend with that patient...sometimes you have...and sometimes frequently...more frequently you haven't got the time to spend with the patient or the family' (FG1 ED RN).

'We are so limited in what we can actually do, the difficulty is we've got so many and I know it's really important but everyone is really important and we are always continuously overloaded here and unfortunately these people don't get anymore care than the next and your having to spread yourself out so thinly so it's very difficult to actually make differences to the care your giving' (FG3 ED Sister)

'We would like to give everybody more time but I think it is towards the end of their life you would like to be able to have a little bit more time to go a little bit more slowly and consider everything' (FG1 ED RN)

'Processing people not nursing' (FG3 ED SIS)

'I think also coming from a ward environment I have had fantastic deaths on the wards for the patient but I was able to spend that time with them and other thing could have waited where as this isn't an environment where things can wait..it's the time aspect' (FG3 ED RN)

### Acutely sick vs. EOL patients

" And it's very difficult you have someone who is about to die and that someone who has just come in dreadful pain and really poorly...where do you go?" (FG1 ED RN)

" That's what we do all the time we are always reevaluating and trying to shuffling....going from bed to bed... Where ever we need to be the most at that time...and I don't think there is an easy answer that's always going to be the case" (FG1 ED RN)

"To a certain degree you think I can't do anymore for you because your passed that point you have to kind of...it sounds horrible but prioritise..." (FG3 ED RN)

"But if you're in resus and there's only three nurses plus two trauma alerts coming in even with all the will in the world you physically can't give them all the time and attention they should get when they are palliative...which they should..." (FG2 ED RN)

'We have to give everyone the same time if possible and the more poorly they are the more erm...that's the person who gets the care' (FG3 ED RN)

'Patients in the department that sometimes we know patients aren't seen till they've been here three hours fifteen minutes especially if we've have major traumas or cardiac arrests coming in' (FG2 ED SIS)

### **Demands of Job Role in ED**

“I think that’s the worst thing and the most frustrating thing that you want to be with the patient and just....sit and hold their hand and talk to them and....but...often it’s the case you just can’t get back to them because there’s just...plenty of other patients that need you...” (FG2 ED SIS)

‘If you were stood with a dying family you are still going to get grief off staff saying oh that patient needs to go to CDU or you know people are queuing down the corridor, there is an element I want to stay but you feel bad for that but the reality is there are people queuing down the corridor they are sick and they need the bed’ (FG3 ED RN)

“As much as you want to give that one patient as much as what you can you got another 60 patients you have got to make sure they are getting absolutely everything and it’s so difficult...you can’t....you can’t put one person above another....you need to be there for absolutely everybody and it’s so hard to do so sometimes” (FG1 ED SIS)

‘I think that’s the worst thing when you actually have to kind of pop in and you know, it’s horrible but you have to go back out cos you’ve got a lot of other jobs to do as well...Its not being able to give them somebody just to talk to or just be there’ (FG3 HCA)

‘And we are expecting to be doing more and more and more on a daily basis extending our roles...and it’s just we are moving away more and more...aren’t we?’ (FG3 ED SIS)

## Appendix 21 - View on Established Interventions

### ABCD Assessment Tool – Positive comments

“Yeah see I quite like that ABCD because in A&E that’s kind of how we work everything is” (FG2 line 451 ED RN 4)

“ Yeah, clear concise” (FG2 Line 452 ED RN 5)

“Yeah it’s a clear thing, its normal to what we do, accept for when you have a palliative patient you apply it slightly differently, just a very quick assessment tool and it makes you think a little bit more about...when you are doing your initial assessment what further steps you could take, so if I was using that I think I would think about things a little bit more go a bit deeper into things, a little trigger” (FG2 Line 454 ED RN 5).

“ Installing something like the ABCD thing that is immediately important to us knowing how to act, that’s the information we need and how to go about that initial assessment, what is important okay what are the first things would you consider about a palliative care patient over and above this...might the actual problem they might have come in with because obviously we know how to deal with the problem they’ve come in with because we’ll tackle it in terms of dealing with these other issues like where they will go after and have they got certain things in place etc...and how to access all this information I think that’s where we struggle...”(FG2 Line 560-566 ED RN 3).

“I think the ABCD one is quite a nice one focussing your attention on the priorities of what the patient needs” (FG3 Line 342-343 ED RN 2).

‘And I think you could use the ABDC one in line with the two stage screening like if...it triggered on this you then use this and you could link the two together couldn’t you? I think it would work quite well...” (FG2 Line 465-467 ED RN 4).

‘I think there’s some very good ideas here...and these are things we need to consider [ABCD]’ (FG1 ED RN)

### ABCD Assessment Tool – Negative comments/Improvements

“ I didn’t like looking at just that ABCD....I instantly thought I don’t like that....we are so used to a very different ABCD and having that and having the two and it is nothing like what we know of now and no I instantly disliked that straight away just because of the lettering...So I didn’t glance at it that much as I just thought no” (FG1 ED RN)

‘Could do with coming up with a different mnemonic using different letters’ (FG1 ED SIS)

‘I think maybe change the words a little bit... It’s quite wordy so maybe we have Airway, Breathing so maybe like have literally have a word for each one’ (ED RN FG2)

‘Like obviously are there any advance directives in place..no..well does that mean we need implement one, does that mean we find out about it you know there’s no..there’s no like like an algorithm almost like a yes or a no answer if there’s not then what can we do if there is then brilliant it ends there. Maybe following that are the relatives here are they aware and things like are there caregivers at the bed side no obviously we were saying we can’t...we can’t err...make sure there’s always defiantly going to be somebody with the patient in resus so the answer to that would be no how can I get hold of them? Well if the patient has a reduced GCS and they are here without any family members then the patients not necessarily going to be able to press the call bell so what can we do? ‘FG2 ED RN)

### **ABCD Assessment – Negative Comments/Improvements Continued...**

It's almost like what you could liken it, make it similar to our DST screening tool just a simple tick box algorithm so they pass yes brilliant and you tick it it's all done they don't it gives you another box to the side okay well do this now or don't do this and I think it's quick and easy for anybody to have a quick reference and just follow it and it gives you all the information there and if it's quick and easy to follow you will find that people will be using and implementing it a lot more because it's not going to be time worthy and as I say its simple so anyone can use juniors, seniors, healthcares, students nurses' (FG2 ED RN)

### **Rapid Two Stage Screening Tool**

"Just looking at the age limit...I don't think there should be an age limit" (FG2 ED RN).

'Especially in this trust as well as they do a lot of young cancers' (FG2 ED RN)

'And even your brain injuries and your anything coming in, we see them all from the age of 18 upwards so I don't think there should be an age limit...that's all' (FG2 ED RN).

"On the two stage screening programme it says stage one it says patients with life limiting conditions on attendance to the ED...There is a lot...more than....than I think the palliative care team could see" (FG1 ED RN).

"To be honest...there's a lot of people coming with life limiting conditions...so stage one is a really big big thing to get PC involved with" (FG1 ED RN).

"I don't necessarily think a special person being here is necessary because predominantly of the financial burden and the burden on the service" (FG1 ED RN 4).

"Is it realistic to have those two people present in the ED twenty four seven? Whose going to finance it?" (FG3 ED Sister)

'Yes [It is more suited to a ward area] because if they are looking to discharge them this is the sort of thing they will look at to be put in place, although I understand the rationale of putting things in place the earlier the better you know' (FG3 ED SIS)

'Stage one is a really big big thing to get PC involved with anyway with anyone with life limiting conditions we'd be more from the EOL point of view' (FG2 ED CN)

### **SPEED Tool – Positive Comments**

"I think the SPEED tool is good in a sense that it does a bit more than like social and therapeutic but I just don't think it would necessarily work in...it does work in one sense but it's a lot all that's got a lot for that one patient and like you say you want a quick sort of.." (FG2 ED RN 2).

"The SPEED tool could be quite useful, when you think how much people can communicate...these are things we can change very quickly I think...like if you've got someone SOB they're not going to be wanting to talk to you...and they can actually just circle, mark, tick highlight that particular area you got right I can deal with that I can sort that out now you know?" (FG3 ED RN 2).

### **SPEED Tool – Negative Comments/Improvements**

'No see my that...I wouldn't necessarily have it in that order you know I mean...I think even the spiritual would perhaps change place with social for me...and the pain sort of then because their in pain' (FG2 ED SIS).

Yeah, it would be very clear cut what the patient has come in with through A&E if they start having problems on the ward then you might use that' (FG2 ED RN).

### **SPEED Tool – Negative Comments/Improvements Continued...**

“The order that it’s in there I presume would be moved around as from an ED point of view, we would go for the physical therapeutic and possibly the psychological and then social and spiritual would be way down the list...” (FG1 ED Charge Nurse).

“I wouldn’t necessarily have it in that order you know I mean...I think even the spiritual would perhaps change place with social for me...and the pain” (FG2 ED Sister).

“The SPEED Tool is quite lengthy” (FG1 ED RN2)

### **PC Champions**

“I think it is good to have palliative champions” (FG2 ED RN)

“Is there a link nurse within ED that do that?” (FG2 ED RN)

“ Well we have nurses for most things in the ED...so you know it wouldn’t be a bad idea if we had someone to communicate to for advice because it’s very hard to take on board everything that’s actually happening in the department...it wouldn’t be a bad idea...” (FG3 ED Sister)

“I think more education as I don’t know who they are” (FG2 ED RN 3)

### **PC referral in the ED**

“I don’t know much about the PC service, I didn’t even know we could contact you” (FG1 ED Sister)

“Do we have on-call PC teams in the hospital or even a PC team?” (FG2 ED RN)

“I didn’t know we could refer to them...we can actually make referrals to them?” (FG3 ED Sister)

“There is lots of discussion about getting PC involved and actually we don’t come down to the department very often, it is rare we get a referral from down here” (FG1 PC CNS)

“We can’t respond as quickly as the acute oncology service...because our caseload is such that we don’t have a member of staff” (FG1 PC CNS)

“Someone we can call for help to say we’ve got this person...here we can’t get them back, they are in the ED or we are having problems what...what would you suggest” (FG2 ED RN 2)

“Staff are quite clued up but It’s the problematic ones that would be needing the referral” (FG1 ED CN)

### **Oncology service**

“The acute oncology service are really good you phone them and they are down here in twenty mins so they are really pro active” (FG1 ED Sister).

“The oncology guys as soon as they book in at oceana [computer based data system] they get an e-mail sent to a generic inbox so whether that be something you could set up for your service, so that as soon as someone who has been highlighted as being a palliative patient you could receive an e-mail and know that they are obviously in the hospital if there is somebody available chase them up or....just so you know who is here and whose not here” (FG1 ED RN).

“ The nurses come on and before you even spoken to them they know that they are here and...sometimes like you say do the same thing with palliatives and their teams that as soon as they come in they kind of we don’t have to ring them up they there’s just something just alerts them to let them know already” (FG2 ED RN 4).

## Appendix 22- Interventions Suggested to Improve End of Life Care in the ED

### Patient Pathway

"A pathway would be nice and education around it" (FG1 ED Sister).

"Some kind of pathway would be useful" (FG2 ED RN).

"We can give the best nursing care here start the ball rolling, start medication, getting the family knowing what is going on ...If we can educate them as best as we can...and get that patient to be comfortable and relaxed it is a better outcome for them and the family"(FG1 ED Sister).

"I think if it is imminent then you should be following some kind of pathway" (FG1 Line 138 ED Sister)

"There's not a set supportive pathway...but if we had someone come through resus who was at the EOL and we called the medical team we can get stuff started, get things prescribed...we can get as much started here to help that patient and save them having to wait" (FG2 ED RN).

"A fast-track pathway we have is for NOF's so to get them up to the ward in... within an hour of coming through A&E and being diagnosed with a confirmed NOF and you have a fast-track pathway that certain things need to be done but then the rest can be done up on the ward like the clerking as such erm...if we were to have a fast-track pathway like yes this patient in PC, yes we've got a community DNR or we have a last dying wish that then you know then the family are here, the family have agreed that this needs to be put in place and the hospital can also we can't go by community papers then...yes okay the patient is comfortable is...they are going to be in the A&E department we need to get them to the ward now...so almost like a another fast-track pathway so that within an hour we have optimised that patients care" (FG2 ED RN)

"Pain, hydration, fluids comfort and treating like if it's an infection" (FG3 ED RN)

"As long as they're pain free and are unaware of any pain what's so ever that's got to be a priority yes" (FG3 ED Sister).

"It's all about communication...just keeping the family informed, involving them as much as they want to be involved or as much as the patient wants them to" (FG1 ED RN)

"It's quick and easy for anybody to have a quick reference and just follow it and it gives you all the information there and if it's quick and easy to follow you will find that people will be using and implementing it a lot more because it's not going to be time worthy and as I say it's simple so anyone can use juniors, seniors, healthcares, students nurses" (FG2 ED RN).

"It's a point of reference isn't it?" (FG1 ED RN)

### Senior support – pathway

"Yeah if we've got something more like this that the juniors can sort of look more...look at then they know they're not scared to make that decisions they are then following like a protocol or a step guide to you know this is what you can do" (FG2 ED RN)

"Yeah and they're quite afraid, they're quite scared of it [EOL] having experience of it in CDU as well they are terrified of it" (FG2 ED RN)

We are quite good at getting people into the community only if we have a good senior on otherwise more junior people are frightened to make the decision' (FG2 ED RN)

## **Liverpool Care Pathway**

'The LCP does dictate that you withdraw all care I don't know, but its goes again the grain doesn't it?' (FG3 ED SIS)

'Yeah it's like saying, if the LCP says if this persons in pain so what you're not going to give them any pain relief? To prevent them being in pain?' (FG3 ED RN)

'It's an EOL pathway it does not mean you withdraw care completely...' (FG3 ED RN)

'So do you think a pathway would be useful to guide care?..The LCP no...' (FG3 ED RN)

## **Documentation**

"I was thinking an alert tag or something like diabetics wear those bracelets...but patients come in wearing them you know something" (FG2 ED RN)

"Passport to care for patients with chronic illnesses you can show at reception used to plan care" (FG1 EDCN).

"Patients with sickle cell have a little printed card with their photograph and treatment plans" (FG1 ED RN).

"The sickle cell patients come in with the information what painkillers they like, what they don't like, how they like it its very specific and having something like that for palliative care would be really good" (FG1 ED RN).

"So we need to make sure that everything is either clearly documented or the patient comes in with something suitable to be able to inform us of the patient condition" (FG2 ED RN).

'Need to ensure paperwork is not just paperwork but on a computer system as it is ridiculous patients are admitted due to lost paperwork' (FG2 ED RN)

'I think that the GP and community nurses need to make sure that the paperwork is in place because...if the patient doesn't come in with a family member or a nurse that even knows what is going on or isn't completely up to date or these documents to say this is my condition you know I am palliative I am EOL not necessarily that this is my community DNR or these are my dying wishes but just so that we are aware of the diagnosed condition and what stage they are at' (FG2 ED RN)

"No current documentation for EOLC, so unless you have a specific performa for EOLC, like you would for specific other care plans...so a list of things what we can do for the patient" (FG3 ED RN)

'To know if that patient is already a palliative patient in the community, how do you have access?' (FG1PC CNS)

A lot of people have got their care records...that they bring with them, if they are on a particular care regime at home...that's useful...then again its a case of how well they fill it out?' (FG1 CN)

'Because that would be a case of having you know the same systems in place in the community...' (FG2 ED RN)

## **Consideration of universal documentation**

"The difficulty with things like that with patients that are palliative and at the EOL is that they often change their mind" (FG1 PC CNS)

'That comes under compliance and whether the nurse's remember to put it back on the patient after they've washed them' (FG2 ED RN)

### **Negatives of Documentation**

"Would introducing new documentation change what we do? Would we give more care? I don't think we need more paperwork" (FG3 Line ED SIS).

"It doesn't get used appropriately the more we get [new documentation]...we are using the care round sheets which can be adapted" (FG3 ED SIS)

### **Trigger System**

"I think also maybe having like a trigger system so that like for example on oceana [computer system used in the ED] you always know when your regulars come in because there triangles next to their name in red and you know how many times they've been admitted so maybe it might be a matter of as soon as this person has been put on a SCP you have a similar thing so perhaps their community matron or whoever it is that's dealing with their PC in the community is alerted that they've called an ambulance they know straight away what's happened and whether they then meet them at the A&E and they can be there maybe to try and get them out of the department as quickly as possible or to meet them at the home and prevent it from happening at all" (FG2 ED RN).

"I think having an online easily system where not just the your not waiting just for a doctor to log on to clinical portal to say...but something that triggers straight away as soon as that person comes into hospital you know they are palliative and this and this are already in place and you're not having to wait for someone else to tell you or if it's really busy doctors don't see patients for hours and hours on end and by that point well they could of gone home"(FG2 ED RN).

"So that as soon as someone who has been highlighted as being a palliative patient you could receive an e-mail and know that they are obviously in the hospital if there is somebody available chase them up or....just so you know who is here and whose not here" (FG2 ED RN).

"It would be useful to us to alert us patients are in hospital" (FG1 PC CNS)

### **Education – Community**

'In the community the relatives then get worried because I didn't expect this to oh my god let's call an ambulance because this isn't meant to happen oh I am not expecting this to happen, they then rush them here. I think in the community maybe some....not saying every situation but some situations the family haven't been as educated or understand what is going to happen, then they panic bring the relatives to hospital and again we are stuck in that cycle" (FG2 ED Sister).

"Education should be for the families as well obviously when they are diagnosed with something that is terminal, then the family can understand it to a certain extent but when that patient takes a rapid decline they then panic and go 999 for an ambulance" (FG3 ED RN).

"Does the education need to be with the ambulance crew to say when they go into that person are they aware this is an EOL pathway and us taken them to hospital" (FG3 ED Sister)

"In the community more often palliative patients get brought to A&E for stuff like say reduced conscious levels or just sort of pain management, it might be the case their thinking the only way we're going to get the appropriate pain management or treatment is to come into hospital because a lot of people don't realise how much can be put into the community pain, like syringe driver and everything and it might be that they haven't quite reached that stage and that what needs to happen and instead of getting hold of the team it's because they think it will take days or something they come straight to the hospital...but you could understand if someone was in pain you would just want to get them sorted, it is something they could do straight away in the team just district nurse could help..." (FG2 RN 2)

'I think as well we sort of have to look at the role of the GP in this...that these patients are phoning' (FG2 ED RN)

### **Education – Managing Expectation in Community**

“No matter how many times you’ve told someone unless they’ve already experienced it once they never expect it just from personal experience of telling my relatives exactly what’s going to happen and when it actually came to it they just sort of weren’t expecting it” (FG2 ED RN 2).

“Imagine that though watching your loved one struggle for their breath...I don’t know whether I could do that...” (FG3 ED Sister)

‘I think the only thing with that [education on community] though from experience is I think its brilliant and we do need more of it but I don’t think it is always going to work no matter what’ (FG2 ED RN)

### **Education – Within ED**

“Just some education on that for all nurses and doctors would be amazing and I think that would be a really beneficial study session [In relation to the pathway in place in the hospital]” (FG1 ED Sister).

“Just so actually everyone knows what’s going on...so everyone like, like ED RN 5 said so she knows what people to ring in a certain situation, so she’s not stuck and then having to go to a senior so that’s all in place...” (FG2 HCA)

“You’ve got palliative care for cancer haven’t you? But you’ve also got patients at the EOL COPD haven’t you we’re all focussing on cancers really. I mean really...A COPD patient that was at the EOL I wouldn’t even know who to go to for that...about that...I wouldn’t have any ideas...I wouldn’t know who to contact about that...” (FG2 ED RN)

“We have so many different illnesses and diseases to look after that it gets very hard to learn how to manage one particular area...you know...so...I think education is the key I think” (FG2 ED SIS).

‘Maybe a lists of hospices that we can try and get people to and don’t have to die in hospital..and the place that they sent them in from maybe they sent them for social reasons that they can’t cope with their care needs so lets try and find somewhere a bit more suitable for them...so a list of hospices in the area that possibly would be able to take the patient’ (FG2 ED SIS).