Perceptions of Hospital-based Clinical Staff on the Role of Speech and Language Therapists in Palliative Care

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Abstract

**Background:** This research originated in response to anecdotal concerns regarding the withdrawal of palliative care (PC) referrals to speech and language therapists (SLTs) in an acute setting. Although a synthesis of the literature identifies the role of SLTs in palliative care in four areas: consultation, communication strategies, dysphagia and holistic care; there remains a lack of clarity around how the role is defined in an acute setting. This study aims to explore how SLTs working in an acute setting perceive their role in PC; to explore how hospital-based clinical staff (HCS) responsible for SLT referrals perceive the role of SLTs in PC; and to present an integrated overview of these findings.

**Methods:** A qualitative research design was implemented using a focus group and semi-structured interviews. SLT and HCS participants were recruited via a gatekeeper internal to the SLT department in an acute hospital setting. 7 SLTs participated in a focus group. 8 HCS participated in semi-structured interviews. HCS consisted of 2 doctors, 2 nurses, 3 medical social workers and 1 dietician. Data was transcribed, anonymised and analysed using thematic analysis and organised according to thematic networks.

**Results:** Three global themes were identified: The role of the SLT in PC; Palliative considerations; and Referral matters. Findings demonstrate that in the patient-centred and evolving speciality of PC, SLTs work as part of a multidisciplinary team, providing mainly dysphagia work with limited fulfilment of their role in communication intervention. It was found that particular factors influence HCS to make or withdraw PC referrals to SLTs.

**Conclusions:** The themes arising from the data reflect that although SLTs are perceived to have a role in PC, especially relating to dysphagia management, a lack of certainty still exists about this role. It is recommended that increased clarity can be facilitated through SLT specific PC education, inter-professional education, intra-professional discussions and guidelines and further research.

**Keywords:** Speech and language therapy, palliative care, role, perceptions, hospital-based clinical staff
Introduction

This research originated in response to anecdotal concerns regarding the withdrawal of previously made referrals to speech and language therapists (SLTs) for palliative care (PC) patients in an acute setting. It was assumed that referrals were withdrawn when patients reached the end stages of their illness. The involvement of SLTs in PC is a recent development in the profession; thus, it is important to understand how the role is perceived in order to ensure that service decisions are made as part of a well-integrated team (Pollens 2012). As the aim of this study is to contribute to the knowledge base regarding the role of SLTs in PC, the current treatment of PC and the role of SLTs in PC in the literature will be synthesised.

The development of palliative care

The World Health Organisation (2002) defines PC as a team based approach that aims to enhance the quality of life of patients and their families facing life-threatening diseases, through the prevention and relief of suffering from physical, psychosocial and spiritual pain. As a relatively young medical field, the provision of PC services for patients with chronic or terminal illnesses has only been reflected in Irish policy documents since 2001 (HSE and IHF 2008). However, a recent study by Kane et al (2015) indicates that due to its rapidly ageing population, Ireland has the fastest rising need for palliative care in Europe. For example, between 2007 and 2011, 80% of reported deaths in Ireland were due to conditions associated with palliative care needs (Kane et al 2015).

In response to this increasing number of people living with complex health-care needs (Dy and Feldman 2012), there is a trend towards the idea that PC should not be narrowed to those who are actively dying but offered from the day of diagnosis in conjunction with life prolonging therapies (WHO 2002). This greater focus on therapeutic intervention early in the course of terminal illness has led to a more holistic psychosocial model of care that takes into account International Classification of Functioning values such as contextual environment and personal factors (WHO 1993) within a team-based framework (Krival 2013). As part of this team approach, the core members of PC teams include medical, nursing and social work professionals; while non-core team members
include chaplains, counsellors, SLTs, physiotherapists, occupational therapists, pharmacists, art and music therapists and trained volunteers (Pollens 2012).

The role of speech and language therapists in palliative care

There has also been an increased focus on the role of the SLT in PC in terms of practice-based evidence and case studies (Pollens 2004; Eckman and Roe 2005; Newman 2009; Roe and Leslie 2010; Pollens 2012; Toner and Shadden 2012; Kane 2013; Krival 2013). Pollens’ (2004) synthesis of the literature on the role of the SLT in palliative care, identifies the role in four areas:

Consultation

As it has been found that SLTs are not typically core members of PC teams (Pollens 2012; Kane 2013), Pollens (2012) emphasises the importance of the consultative role of the SLT with core team members within the PC model. An initial SLT consultation for a patient receiving PC may involve discussing patient and family concerns regarding communication and swallowing, assessing communication and swallowing needs, feeding back information, collating relevant information from other members of the multidisciplinary team (MDT) and recommending follow-up as necessary (Pollens 2012).

Communication strategies

Several studies have highlighted the high incidence of communication impairment among patients at the end-of-life (Jackson et al 1996; Salt and Robertson 1998; Morita et al 2003). For example, in a sample of 12 cancer patients receiving PC, Salt and Robertson (1998) found that 11 of the 12 participants scored within the impaired range for aspects of communication such as story recall, naming, sentence comprehension and motor speech. Furthermore, they report that many of their participants expressed concerns about their ability to communicate. The researchers concluded that an aspect of the role of the SLT during the terminal stage of patient care is to introduce strategies for supporting communication function in order to maintain skills and maximise potential for as long as possible. Cohen et al (2009) highlight evidence-based therapies for PC populations that present with voice and motor speech disorders; for example, Lee Silverman Voice Treatment for patients with Parkinson’s disease. Furthermore, for patients with declining disease trajectories such as motor neuron disease (MND), voice
banking enables patients to pre-record messages on electronic communication devices in order to preserve their voice and sense of self (Radtke et al 2011).

**Dysphagia**

Dysphagia is a symptom that occurs frequently in progressive terminal illness, especially with diseases of the upper respiratory tract; progressive neurologic disorders such as MND, Parkinson’s disease and multiple sclerosis; dementia; and as a result of the general decline of patients nearing the end-of-life (Groher and Groher 2012; Goldsmith and Cohen 2014). Therefore, an aim of SLT intervention is to maximise the patient’s swallowing function in order to promote safe, comfortable and positive feeding experiences (Ryan et al 2014). Given the emphasis placed on quality of life for patients who are receiving PC, feeding for the sake of enjoyment, social interaction and intimacy with carers is an important aspect of SLT involvement. For patients with advanced-stage dementia, it is the role of the SLT to use the available evidence-base (Finucane et al 1999; Gillick 2000; Palecek et al 2010) to inform the patient while they are still cognitively competent, caregivers and team members about risk of aspiration so that an informed decision regarding oral or alternative nutrition can be made (Eckman and Roe 2005; Groher and Groher 2012).

**Holistic care**

In order to promote true quality of life, it is important for SLTs to contribute to the holistic care of the patient through recognising the impact of the illness on the patient and their family and providing appropriate support (Ryan et al 2014). This aspect of the SLT role in PC requires effective inter-professional communication and collaboration in order to facilitate a holistic and patient-centred consideration of the personal and environmental factors that may influence the timing and nature of intervention (Pollens 2004; HSE and IHF 2008; Pollens 2012).

**Current research**

Despite the identification of the need for the role of SLTs in PC in the literature, SLTs have reported anecdotally that they are not routinely involved in PC, receive few referrals and are even refused authorisation to consult (Pollens 2012; Krival 2013). Oliver and Webb (2000) found that in the UK and Ireland, SLTs were involved in specialist palliative care in only 25% of the home care services and 21% of the day hospices
surveyed. For the referral of patients for insertion of a percutaneous endoscopic gastrostomy (PEG), it was found that the assessment was carried out by a nurse or medical team in the majority of cases; only a minority referred for a specialist assessment by an SLT (Oliver and Webb 2000). Although PC has developed in the 15 years since this study was conducted, it supports anecdotal concerns regarding low levels of involvement of SLTs in PC. Furthermore, O’Reilly and Walshe (2015) conducted an international mixed methods survey on the perspectives of 322 SLTs from 6 countries on their role in PC. The study’s findings suggests that this area of practice is under-resourced, under-acknowledged and under-developed. O’Reilly and Walshe (2015) also raise the question of whether a lack of MDT recognition of the role is having an impact on PC service delivery. This question reflects a general lack of clarity surrounding how those responsible for referrals to SLTs perceive and define the SLT’s role in PC.

Overall, the current literature regarding the role of SLTs in palliative care is mainly based on anecdotal clinical experience and case studies and for the most part is written from the perspective of SLTs. In addition, the literature focuses on SLTs working in hospices, with a lack of studies focusing specifically on the role in acute settings. This is a pertinent issue as the majority of people spend the end of their lives in hospitals or medical centres (National Centre for Health Statistics 2005 cited in Toner and Shadden 2012). Therefore, the need for the inclusion of a greater number of perspectives and settings and more rigorous investigation on perceptions of the role of SLTs in PC was identified.

**Methodology**

**Design**

Carried out in a Dublin hospital, the study used a qualitative research design in order to achieve the following aims:

1. To explore how SLTs working in an acute setting perceive their role in PC.
2. To explore how hospital-based clinical staff (HCS) responsible for referrals to SLTs perceive the role of SLTs in PC.
3. To present an integrated overview of these findings.
A focus group with SLTs and semi-structured interviews with HCS were selected as the methods of data collection. Different methodologies for data collection were chosen as organising a focus group to accommodate the HCS was not practically feasible. Focus groups and semi-structured interviews are appropriate methods of data collection for qualitative research as they allow participants to openly discuss their perceptions and opinions on the topic. A limitation of focus groups is that due to group dynamics, one particular voice may dominate the discussion, while others may be reluctant to share opposing opinions. The researchers aimed to minimise this by giving all participants an equal opportunity to express their opinions and to write down and submit any additional thoughts at the end. A limitation of semi-structured interviews is the potential of the Hawthorne effect, whereby participants feel the need to please the interviewer with their responses (Bowling 2009). The researchers aimed to minimise this by reassuring participants that all opinions were welcomed and that there were no right or wrong answers.

**Sampling and recruitment**

Participants for the focus group were recruited through convenience sampling from the hospital’s SLT department. This was done through the circulation of an information sheet (See Appendix A) to department staff via an SLT gatekeeper internal to the hospital. Participants for the semi-structured interviews were recruited similarly via convenience sampling; the gatekeeper circulated the same information sheet to different medical teams in the hospital. Inclusionary criteria for participation indicated that SLTs of all grades from the hospital’s SLT department could participate in the focus group and referring members of clinical staff such as doctors, nurses, medical social workers and dieticians could participate in the semi-structured interviews. In total, 7 SLTs and 8 HCS participants were recruited for the study. Re-occurrence of the same codes indicated that data saturation had been reached after 1 focus group and 8 semi-structured interviews.

**Procedures**

Prior to commencement of data collection, the study was approved by the hospital’s ethics committee. The focus group took place in a room in the SLT department for convenience and lasted 45 minutes. An introductory script and questions were pre-prepared (See Appendix B). Questions were developed based on the research aims around
the main domains of: role of the SLT in the hospital, experiences and caseloads in PC and referral. One researcher acted as moderator, one researcher acted as time-keeper and one researcher acted as note-taker. Participants provided written consent prior to the commencement of the focus group (See Appendix C). The focus group was audio-recorded. The audio-recording was then uploaded to a password protected computer, deleted from the audio-recorder, transcribed, anonymised and then deleted from the computer. An anonymised summary sheet of the topics discussed during the focus group was disseminated to the participants in order to confirm validity of recorded data and tentative interpretations (See Appendix D).

On average, the semi-structured interviews lasted 10 minutes. They took place in the SLT department, a ward office and at a conference room in order to accommodate the participants. The pre-prepared introductory script used for the focus group was modified appropriately for the semi-structured interviews and a similar line of questioning was followed (See Appendix E). Participants provided written consent prior to commencement of the semi-structured interviews (See Appendix C). In relation to audio-recording the same procedures were followed as for the focus group. Member-checking was not conducted due to the individual nature of the semi-structured interviews.

**Data analysis**

Data from the focus groups and semi-structured interviews were analysed together in order to present an integrated overview of the perception of SLTs and HCS on the role of SLTs in PC. This was justified by the similarities that emerged from both data sets. The researchers aimed to minimise the limitations of merging data sets collected via distinct methodologies by using similar question formats in order to limit variance in the main stimulus questions and by reading the same script at the start of data collection. In order to ensure reliability and validity of the study, distinctions were made between the perceptions of the SLTs and HCS where relevant in order to highlight contrasting or similar perspectives. A limitation of this approach to analysis is accounting for differences in group versus individual dynamics on the data collected.

Data was transcribed, anonymised and analysed using thematic analysis and organised specifically according to thematic networks (Attride-Stirling 2001). Six steps of analysis were carried out as follows:
1. Data was transcribed and anonymised
2. Nodes were assigned
3. A coding framework was devised
4. Codes were grouped into categories
5. Thematic networks were constructed
   a) Basic themes were selected
   b) Basic themes were rearranged into organising themes
   c) Global themes were deduced
   d) Thematic networks were illustrated
6. Networks were verified and refined

An example of the above process has been provided in Appendix F.

Particular strategies were implemented throughout the process in order to ensure the validity and reliability of the analysis:

- The researchers immersed themselves in the data before transcription and analysis through listening and active reading of the transcripts and making notes of issues of potential interest.
- Transcriptions were checked by a second listener to help clarify points at which intelligibility was low.
- Each stage of the coding process was recorded and data was clearly assigned or re-assigned to codes at each stage.
- Mind maps were used in order to visually present the development of coding.
- Credibility was enhanced by the repeated debate of underlying codes, meanings and groupings.
- Checking the reliability of coding was confirmed by asking an independent third-party to assign random codes to the basic theme they felt most appropriate. The third-party was able to do this accurately 7 out of 10 times.
- Wordle (Freinberg 2013) was used to generate a word cloud using the data nodes. The word cloud gives greater prominence to words that appear most frequently in the text. This was used to check that the most prominent words were reflected in the themes that emerged (See Appendix G).
Results
Sample

The 7 SLTs that participated in the focus group included 1 basic grade and 6 senior grade SLTs. The 8 HCS that participated in the semi-structured interviews included 2 doctors, 2 nurses, 3 medical social workers and 1 dietician. SLT and HCS participants were randomly assigned numbers as per Table 1:

<table>
<thead>
<tr>
<th>Focus group participants</th>
<th>Semi-structured interviews participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>SLT 1</td>
<td>HCS 1</td>
</tr>
<tr>
<td>SLT 2</td>
<td>HCS 2</td>
</tr>
<tr>
<td>SLT 3</td>
<td>HCS 3</td>
</tr>
<tr>
<td>SLT 4</td>
<td>HCS 4</td>
</tr>
<tr>
<td>SLT 5</td>
<td>HCS 5</td>
</tr>
<tr>
<td>SLT 6</td>
<td>HCS 6</td>
</tr>
<tr>
<td>SLT 7</td>
<td>HCS 7</td>
</tr>
<tr>
<td></td>
<td>HCS 8</td>
</tr>
<tr>
<td>1 basic grade, 6 senior grades</td>
<td>2 doctors, 2 nurses, 3 medical social workers, 1 dietician</td>
</tr>
</tbody>
</table>

Overview of themes

Three global themes emerged from the data: The role of the SLT in PC; Palliative considerations; and Referral matters. The quotations used to support the findings are shown as part of the thematic networks process in the appendices (See Appendix H).

Global theme 1: The role of the speech and language therapist in palliative care

The role of the SLT in PC encompasses the notion that the SLT has three main domains of input in PC. Although SLTs are currently perceived to have a team-based role in PC, this role faces certain challenges (Table 2).
### 1.1 Current role

The role of the SLT in PC is perceived by SLTs and HCS as pertaining to three areas of input. Firstly, SLTs and HCS reported that dysphagia was their main area of input in PC: 

“We are mostly called upon for swallow management” (SLT 1); “it’s very much dysphagia rather than communication” (HCS 4). As part of this it was acknowledged that SLTs had a role in weighing the risk of aspiration and safety with patient comfort. While the perception that SLTs play a role in facilitating communication through various communication strategies and aids was reflected in the focus groups and semi-structured interviews, some HCS voiced the opinion that SLT communication input was not suitable at end-of-life:

*When people are very near the end of their final journey there would be no need for SLT services in relation to communication* (HCS 8).

Contrastingly, the SLTs felt that there was still more that they could offer in this area: “I know there’s been studies...of our role and I don’t think that’s fully implemented in terms of communication” (SLT 6). Thirdly, it became clear from the SLTs and HCS that part of the role of the SLT at end-of-life is to step back and take an indirect role in management. SLTs and HCS highlighted the role of the SLT in providing consultation for team members as well as working with the family:

*They may not need to see the person themselves but they may need to see the family members because the family members get very distressed* (HCS 8).
1.2 Team working

It emerged from the semi-structured interviews that the SLT role in the hospital was perceived as valuable: “Speech and language therapy is very highly respected within the hospital” (HCS 3). The SLTs reported to rely strongly on the MDT for information and support in PC: “I’ve gleaned a lot from the team” (SLT 1); “You really need them” (SLT 4). The importance of discussion between MDT members in PC was recognised by the SLTs and HCS. For example, one HCS stated that: “It’s not just about sending out the referral; we engage, we talk” (HCS 8). The semi-structured interviews also captured the sense that team work ensured best practice and the best understanding and inclusion of the role of SLT:

When you have an MDT focused approach, the (SLT) role is important, it’s understood, and it’s appreciated. If you don’t have an MDT approach then it’s a little bit more haphazard (HCS 6).

1.3 Challenges to the role

A challenge to the role of SLTs in PC that emerged from the focus group was a lack of confidence in what SLTs could offer generally in PC and specifically in relation to counselling the patient and family. Fears of being intrusive were prominent: “Am I just interfering and causing more problems?” (SLT 4). There was a sense that the role of the SLT was not clearly defined: “I’m not sure what I can offer a lot of the time…” (SLT 5). The SLTs’ perception was that they had not received adequate training in PC or on how to have end-of-life conversations: “I think it’s a gap in even undergraduate training…of how to talk about things like that with patients” (SLT 1). The HCS reported that they had not received any formal education on the role of SLTs prior to their jobs. Contextual challenges of working in a hospital such as lack of service continuity between the hospital and hospices, were raised by the focus group; although “we’re making these very informed and holistic decisions early on” (SLT 1) the person may spend the end of their life “in a setting where we don’t know if those will be carried out…” (SLT 1). SLTs and HCS recognised that consistency of SLT involvement varied across the hospital depending on the team and professionals involved in the patient’s care.
Global theme 2: Palliative considerations

Palliative considerations encompasses the notion that PC is a holistic and quality of life centred speciality. Due to the evolution of PC in recent years, there is still ambiguity regarding its definition and a need to identify how SLTs fit into this developing area (Table 3).

<table>
<thead>
<tr>
<th>Global theme</th>
<th>Organising themes</th>
<th>Basic themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative considerations</td>
<td>Evolving speciality</td>
<td>PC development</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Lack of clarity</td>
</tr>
<tr>
<td></td>
<td></td>
<td>SLT role development</td>
</tr>
<tr>
<td></td>
<td>A holistic approach</td>
<td>Quality of life</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Choice</td>
</tr>
</tbody>
</table>

2.1 Evolving speciality

The perception of SLTs and HCS was that PC has changed in recent years: “It’s not just actively dying” (HCS 1); “The continuum is much broader now” (SLT 2). From an SLT perspective, this represented a continuing evolution:

It’s still emerging and we’re still discovering what it really means to be palliative or to be at the end of your life (SLT 1).

Due to this evolving nature, both groups described PC and its terminology as “nebulous” (HCS 8) and representing a “grey area” (SLT 4). For the SLTs, this meant difficulty interpreting it: “You find yourself asking “how palliative?”” (SLT 1). Data from the focus group indicated that due to the development of the SLT’s role with the evolution of PC, there is a need to educate team members about the SLT’s role in PC: “We do have an onus to educate teams, especially in communication” (SLT 2). However, it was highlighted that there is first a need to define this role:

We need to identify what that role is specifically as a group of therapists and as a professional standard first (SLT 5).

2.2 A holistic approach

Both groups emphasised the prioritisation of quality of life for PC patients and how this sometimes entailed a balancing act with safe end-of-life feeding. The focus group highlighted that dysphagia and communication were not seen by other professions as
symptoms that had an impact on pain. One SLT stated that there was: “Poor understanding that comfort doesn’t always mean eating and drinking whatever you like” (SLT 1) and that they had seen patients in significant distress due to aspiration pneumonia. Another SLT had experienced a patient with significant aphasia for whom quality of life meant being able to communicate with her family at the end of her life: “That patient...was so devastated and had so much she wanted to say to her family” (SLT 2). Although there was agreement between both groups that quality of life was paramount to PC, a feeling among SLTs existed that there was lack of clarity regarding what exactly constituted comfort:

*While you do feel as if you’re doing something beneficial to improve the comfort and quality of life...you don’t know how that is being construed or perceived by family* (SLT 1).

SLTs and HCS acknowledged the importance of including families in decision-making, following their wishes and giving them the appropriate space: “It's all about family...not being interrupted too much by lots of different people” (HCS 7). The focus group also raised the issue of the importance of taking into account the patient’s choice and letting their decisions inform care. SLTs and HCS agreed that PC should be tailored to each individual’s needs.

**Global theme 3: Referral matters**

Referral matters encompasses the notion that particular factors influence HCS to make or withdraw PC referrals to SLTs (Table 4).

<table>
<thead>
<tr>
<th>Table 4 Overview of Referral matters</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Global theme</strong></td>
</tr>
<tr>
<td>Referral matters</td>
</tr>
<tr>
<td>Barriers to access</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

3.1 Specific factors

According to the SLTs and HCS, a patient’s prognosis and the team they are under affects the level of SLT referrals: “Certain teams in the hospital will refer... but other teams are more unsure” (SLT 3). For example, for populations with neurologically degenerative
diseases, high levels of referrals were reported. The HCS highlighted that a patient’s alertness or stage in their illness often fluctuated and this influenced whether or not an SLT referral was considered appropriate: “Sometimes in PC people’s conditions change very quickly” (HCS 7). In relation to the timing of the referral, SLTs and HCS acknowledged that it was “important to refer early” (HCS 2) to SLT in a PC diagnosis as it allows the SLT to document future wishes regarding communication and feeding before deterioration in cognitive or communicative functioning, to build rapport with the patient and to put in place communication and swallowing management.

3.2 Barriers to access

There was a lack of consensus between the SLTs and HCS regarding the occurrence of withdrawal of PC referrals to SLT. It was stated in the focus group that it “happens a lot” (SLT 4) and that involvement with the patient is given a “blanket no” (SLT 4) from HCS. However, the HCS did not consider withdrawal an issue and stated that it occurred following team agreement and discussion when patients were actively dying and management was to be kept to “Minimum intervention of what absolutely needs to be done” (HCS 3). Some SLTs did not consider it an issue either and stated “It can be the opposite of the team wanting to withdraw the referral” (SLT 3) and that “If you felt you really had a role it wouldn’t be difficult to push for it” (SLT 1).

The SLTs’ perception was that the number of referrals received depended on individual knowledge:

We might have someone who knows loads about what speech therapists do and have to offer...so then we get loads of referrals for that 6 months...when that person moves out we might have someone who has less experience...and less awareness of what we see our role as....and then (the number of referrals) wanes off again (SLT 3).

Referrals were also perceived by SLTs to be influenced by the knowledge of certain teams:

They would generate us minimal referrals...that surprises me because I would have thought they’d be well placed to generate a referral (SLT 1).

Overall, SLTs perceived that generally there was a lack of awareness among HCS of what SLTs can offer: “I don’t think they have that knowledge that we do more than just modify (liquids)” (SLT 2); “From the MDT’s perspective I think they’ve probably poor understanding of our role in terms of communication” (SLT 2). Similarly, some of the HCS reported that not everybody would perceive SLT as a useful resource in PC; others stated their own lack
of knowledge and experience in the area: “It was something I’d never considered before to be honest with you” (HCS 3). Furthermore, it was highlighted that perspectives on the appropriateness of SLT input at end-of-life vary among HCS and range from thoughts such as: “There is a need for SLT involvement to end-of-life” (HCS 6) to “I do think SLTs have a role in PC but maybe not so for the patient in the later stages” (HCS 8).

Discussion
This qualitative study collected and presented perceptions on the role of SLTs in PC from the perspectives of SLTs and HCS working in an acute setting. Since these perspectives have not previously been accounted for in the literature, this research aims to guide future research and patient-centred clinical practice. As demonstrated by the themes presented in the results, the role of the SLT in palliative care is complex and influenced by a range of factors internal and external to the SLT profession. Findings pertinent to achieving the study aims will be discussed under the following headings.

Speech and language therapist perceptions

Potential for greater role in communication
Similar to the primary roles described by Pollens (2004), the SLTs perceived their input in PC in terms of dysphagia, communication and consultation work. The SLTs identified their main involvement in PC to be related to dysphagia and that their potential role in communication at end-of-life was not fully recognised or implemented. This finding adds a new perspective to the literature as there is currently a dearth of research that reports variation in SLT involvement with PC patients across areas of expertise such as dysphagia and communication. Furthermore, the SLTs had experienced how communication intervention had improved quality of life for patients but there was a lack of awareness regarding this role. Pollens (2012) recommends that in settings where SLT referrals for PC patients are dysphagia related, SLTs should advocate the equal importance of their role in communication.

In support of this recommendation, Tulsky (2005) highlights the importance of effective communication at end-of-life for facilitating patient and family-centred discussions and decision-making. As communication impairment is common among patients at the end-of-life across a number of illnesses (Jackson et al 1996; Salt and Robertson 1998; Morita et al 2003), this represents a challenge to health care
professionals providing quality of life focused patient-care. Radtke et al (2011) also found that in cases where Augmentative Alternative Communication (AAC) intervention was implemented, medical professionals reported enhanced communication efficiency and an ease of suffering of critically ill patients with communication difficulties. Therefore, the literature affirms the SLTs’ perception that communication intervention can improve quality of life for PC patients and that there is a need to increase their communication input at end-of-life. However, further research and a more extensive evidence-base is required in order to support the development of this area of expertise at end-of-life.

Lack of training, lack of confidence, lack of guidelines

Eckman and Roe (2005) cite a survey of SLTs carried out by Cruikshank and Wilkinson (1998), in which SLTs highlighted the obstacles they faced when working with terminally ill patients. These issues included a lack of specialist training and knowledge regarding disease and treatment effects and confidence in their role in the management of patients receiving PC. These challenges reflect those that arose from the current study: the SLTs perceived that they lacked confidence in the area of PC, especially when patients were at the end-stages of care and when they were expected to provide counselling to patients and families or engage in conversations about dying. The SLTs also reported a lack of sufficient training in PC, both during their formal qualifications and professional careers. Correspondingly, Walshe and O’Reilly (2015) and Mathisen et al (2011) report the need for specialist training and education for SLTs in the area of palliative care. Rivers et al (2009) suggest that SLTs need education during qualification on death and dying in order to minimise the professional and personal impact of working with patients at end-of-life which in turn has an impact on the quality of care the patient and family receive (Rivers et al 2009).

Furthermore, in relation to confidence and guidelines, Roe and Leslie (2010) acknowledge the difficulty of ‘ending the therapeutic relationship’. As stated by the National Council for Hospice and Specialist Palliative Care Services (2000), knowing when to intervene and when to step back is a particularly challenging aspect of PC management that lacks a specific protocol for SLTs. These challenges were reflected in the finding that the SLTs are uncertain about what they can offer patients at different stages of their care; and their feeling that there is currently a lack of professional guidelines and a need for a professional discussion about their role in this area. To highlight these points, there is
currently no Irish Association of Speech and Language Therapists (IASLT) position paper on the role of SLTs in PC or SLT Special Interest Group on PC in Ireland. The need for a professional position paper was also highlighted by O’Reilly and Walshe (2015).

Hospital-based clinical staff perceptions

Not always appropriate

As the perceptions of referral sources on the role of SLTs in PC are not addressed in the literature, the perceptions of HCS can only be loosely and cautiously compared to a descriptive qualitative study by Nelson et al (2012) that looked at how the beliefs held by district nurses made them reluctant to refer PC patients for physiotherapy. A number of Nelson et al’s (2012) findings corresponded with the results presented in this study. These included the belief that referral to physiotherapy would lead to too many professions being involved with the patient. Similarly, the results presented the perception of HCS that referrals are not always necessary due to the need to keep management to a minimum. As the priorities of end-of-life care are maximising family time, indirect work in the form of consultation may be perceived as more appropriate than direct work (Pollens 2012). The perception that SLTs’ input at end-of-life, especially in relation to communication, is not appropriate is also in line with Krival’s (2013) suggestion that some health care professionals believe that SLT is not compatible with palliation as they perceive the goal of intervention as rehabilitation. These perceptions may account for why HCS perceived it as appropriate to withdraw referrals from SLT when the patient is actively dying, that is, the patient only has “hours or days of survival” (Hui et al 2014).

An integrated overview

Defining the role: still a way to go

The finding that the SLTs and HCS believed that SLTs have a role in PC is supported by a growing literature on the topic (Salt and Robertson 1998; Eckman and Roe 2005; Pollens 2004; Roe and Leslie 2010; Pollens 2012; Toner and Shadden 2012; Kane 2013; Krival 2013; Walshe and O’Reilly 2015). The perception expressed by the SLTs and HCS that the SLT role in PC is founded in an MDT approach that aims to enhance patient quality of life is consistent with definitions of PC in the literature (WHO 2002; Pollens 2004; Pollens 2012; Krival 2013). The results indicate that HCS and SLTs acknowledge the importance of SLTs’ dysphagia input for patients receiving PC. Given that SLTs’ scope of
practice includes evaluating risk, making safety recommendations and educating and reassuring family around dysphagia (IASLT 2012), the finding that HCS generally value SLTs’ expertise in the area of end-of-life feeding was expected from this study.

However, the results of this study have also demonstrated that a lack of clarity about the role still exists. According to Roe and Leslie (2010), in ideal PC provision, team members are mutually aware of each other’s roles and clinical markers. Despite the evident effect of communication and swallowing on quality of life for PC patients, uncertainty about when to refer to SLT and their role in PC exists among other healthcare professionals (Eckman & Roe 2005; Roe and Leslie 2010; Pollens 2012, Walshe and O’Reilly 2015). Similarly, the results demonstrate that SLTs believe that their role in PC is influenced by how HCS perceive their role. Due to the perception that some HCS do not have a full awareness or understanding of what SLTs can offer PC patients, the SLTs were unsure if they were maximising their involvement with PC patients. This was reflected in their report of low levels of referrals from certain teams and withdrawal of referrals at end-of-life. Similarly, some HCS reported that they did not have knowledge of and had never previously considered or received training in the area of the role of SLT in PC. This is in line with a second finding from Nelson et al (2012) that the district nurses believed they had limited contact, knowledge, or experience of physiotherapy or physiotherapy interventions. Therefore, SLTs should be aware that the HCS depend on direct contact with the SLTs in order to learn about the SLT’s role generally in the hospital and specifically in PC.

A broad spectrum of care

PC represents a broad spectrum of care from early diagnosis to the end stages of the patient’s illness (Krival 2013). Overall, the results of this study reflect a lack of clarity surrounding the different roles of SLTs at different stages of PC from both the SLTs’ and HCS’s perspectives. The varying terminology captured in this study such as PC, end-of-life and actively dying, indicates that correspondingly, health care professionals working in this area may have a broad spectrum of roles within PC. Pollens (2012) identifies different aims of SLTs depending on where the patient is in their care: traditionally when SLTs work with patients with neurological, oncological or other diseases, the goals of therapy are to reduce impairment, increase functional abilities and maximise opportunities for social
participation (WHO 2012 in Pollens 2012). When the condition is degenerative, therapy focuses on maintaining and supporting function.

For example, a mutual perception of the role of SLT in PC from both SLTs and HCS was the importance of referral to SLT early in the diagnosis. The importance of intervention early in the diagnosis is advocated in the literature, especially in relation to terminal and degenerative illnesses such as dementia. The RCSLT position paper on dementia (2014), states that “Early speech and language therapy is crucial so that people with dementia and their carers have their needs met in a timely way” (RCSLT 2014, p. 6). In relation to early referral for feeding issues, Groher & Groher (2012) advise that patient wishes regarding feeding should be discussed early in the PC process so that an informed decision can be made and appropriate management put in place in advance.

Comparatively, patients with such conditions who are considered at end-of-life, require “a different type of speech and language services which are guided by the context of the physical, social and psychological status of the patient” (Pollens 2012, p. 139). This study has identified that it is at this point that the SLT role and PC terminology become less clear among the SLTs and HCS, as the determinants of comfort and quality of life becomes individually defined. This finding is unsurprising given the lack of consensus in the literature regarding what it actually means to be at ‘end-of-life’ and the lack of research into the role of SLTs at end-of-life (Toner and Shadden 2012). Therefore, in order for PC to be truly effective in maximising patient and family comfort and wishes, SLTs need to understand where the patient is on the palliative continuum and identify how their role corresponds appropriately; SLT services must be flexible and modified as the patient’s condition declines (Pollens 2012). Similarly, HCS as well as SLTs need to understand the different aspects of the SLT’s role in PC as it adapts to meet the needs of the PC patient.

Limitations and further research
As tends to be the case in qualitative studies, sample size dictates that results are not generalizable to all SLTs and other HCS working in acute settings. Therefore, the results of this study should be interpreted with caution. In terms of within setting generalisability, the semi-structured interview participants did not represent HCS from all teams across the hospital and therefore results cannot be generalised to all teams within the acute setting. The SLT sample however, represented a significant proportion of the
SLT department. Due to confidentiality reasons specified by the study’s conditions of ethical approval, the opinions that arose from each HCS profession and team were not specifically identified and therefore the study cannot distinguish or account for different perceptions among professionals and teams. Methodological limitations that may affect the validity of the study have been expressed and accounted for in the methodology section.

Capturing perceptions of specific HCS professions or specific teams across a more representative range of settings is an area of further research that would add to a greater understanding of the role of SLT in PC. Furthermore, as suggested by the emphasis of patient and family centeredness in PC as highlighted in the results, this study only provides perceptions of professional care-givers; the perceptions of those receiving PC, that is the patients and their families, are not directly represented. The literature has explored perceptions of PC patients (Seibel et al 2014) but never on the role of SLTs in their management. Exploring how patients and family members perceive the role of the SLT in PC would add an important insight to our understanding of the role of SLTs in this area.

**Conclusion**

The nature of PC is complex with quality of life and comfort meaning different things to different people. Although the role of SLTs in PC is valued and prioritised in terms of dysphagia, ambiguity still exists about what constitutes comfort at end-of-life. The perceptions captured in this study indicate that further advances are needed in order to fully understand the role of SLTs in PC, especially in terms of communication at end-of-life. SLTs struggle with their own confidence and lack of training in PC, as well as the range of conflicting perceptions held by other HCS about their role in the area. Future research on the role of SLTs in PC needs to explore perceptions from HCS responsible for directly overseeing PC management across a greater number of acute settings, how patients and families perceive the role of SLTs in PC and the SLT role in communication at end-of-life.

**Clinical implications and recommendations**

*Need for inter-and intra-disciplinary education*

- This study recommends that in this particular setting, SLTs need to learn more about working in PC. A suggestion of how to achieve this goal is to increase the inclusion of PC into the speech and language therapy qualification curriculum.
Beyond qualification, Pollens (2012) suggests that SLTs should attend PC educational sessions provided by their facility. The findings of this study also suggest that SLT departments in acute settings should highlight the need for training that is specific to SLTs.

- Based on the results of this study, it is recommended that SLTs as a profession need to facilitate a discussion on their role in PC. Recommendations for how to achieve this is to start an IASLT PC special interest group, facilitate an IASLT conference discussion on the topic and develop an IASLT position paper on the role of SLT in PC. At a work place level, an in-department journal club to encourage keeping up-to-date with the literature on SLT in PC is suggested.

- The results of this study propose that SLTs need to be responsible for advocating their role in PC, especially concerning communication. It is implied that SLTs need to be aware that HCS knowledge of their role depends on learning from and interacting directly with them. As suggested by Pollens (2012), a way to further HCS education on the role of SLTs in PC, is to hold inter-disciplinary presentations on the dysphagia and communication roles of SLTs in PC. Biddle and Mitchell (2008) reports successful outcomes for this form of inter-disciplinary education.
Reference list


Appendices
Appendix A: Information sheet

PARTICIPANT INFORMATION LEAFLET

Date: November 2014

Version No: 2

The purpose of this information sheet is to give you the information about our study so you can make an informed choice about whether to participate or not. Please read this carefully before deciding whether or not to participate.

Research Study Title: Perceptions of hospital-based clinical staff of the role on speech & language therapists in palliative care.

What is the purpose of the research study?

Speech and language intervention is a relatively new contribution to the area of palliative care (end of life care) and Speech and language therapists (SLTs) are receiving an increasing number of referrals to their services from their colleagues in other disciplines (specifically medical and nursing disciplines).

The aim of this study is to explore the perceptions of both SLTs and their hospital clinical colleagues regarding the role of the SLT in palliative care.

- This study is being carried out as part of an academic qualification to meet the requirements of the MSc in Speech and Language Therapy at the University of Limerick.
- The study findings may inform service development in this area.

Who can take part?

- Hospital doctors, nurses, medical social workers and dieticians who work with patients receiving palliative or end of life care.
- Hospital SLTs.
- The number of participants required is 8 clinical staff (in total across the 4 disciplines of doctors, nurses, medical social workers and dieticians), and 8 SLTs.

Why have I been chosen?

- You fit the above criteria.
- The SLT study organiser at Hospital has identified you as a possible study participant and sent you this information, with the researchers’ contact details.
• If you are a doctor, nurse, medical social worker or dietician, and you agree to participate you will be contacted by one of the 3 Research Assistants (University of Limerick Students) to arrange an appointment for an individual interview. If you are a SLT, and you agree to participate, you will be contacted by one of the 3 Research Assistants (University of Limerick Students) to arrange a group appointment time for a focus group discussion. These will take place in Hospital.
• For participants who are not SLTs, only the Research Assistant will know that you have participated in this study. Your name will not be released to any other person involved in the study, anyone else in the hospital or during the write up of the research.
• SLT participants will know other SLT participants in the focus group, but your name will not be released to any other person involved in the study, anyone else in the hospital or during the write up of the research.
• The name of the hospital will not be identified in the study during write up of the data, or for publication.

What will happen to me if I take part?

• Hospital doctors, nurses, medical social workers and dieticians who agree to contribute will be asked to participate in a once-off, one-to-one semi-structured interview of 20-25 minutes duration with a Research Assistant.
• Hospital SLTs will be asked to participate in a once-off focus group (of 8 Hospital SLTs) lasting 30-45 minutes which will be facilitated by the Research Assistants.
• Exact locations in Hospital will be agreed and confirmed with participants nearer to the time.
• This study is specific to Hospital and will not be carried out on any other sites.
• At the beginning of the interview and focus group, you will be asked to sign a consent form. The interview and focus group will then be audio recorded for later transcription. Once the interviews are over, recorded data from the interviews will be downloaded to a password protected computer and immediately deleted from the recorder. Audio recordings will only be available to the Research Assistants, and to Dr. Arlene McCurtin – University of Limerick Co-ordinator. The audio-recordings will be transcribed and then deleted from the computer. Data will then be anonymised before analysis takes place. There will be no audio or identifying information of your participation. This includes identification of your discipline, except if you are a speech and language therapist.
• On conclusion of the study, the data will be kept in the office of the Co-Investigator, Arlene McCurtin for a period of seven years as dictated by University of Limerick Research Ethics requirements. Data will be destroyed in May 2022.
• Participants can withdraw at any time up to the end of the semi-structured interviews/focus groups. Focus group participants may leave the room if they wish to withdraw once the groups have started. Their data will be removed from the recording on request.
Who is organising the research study?

- There are co-ordinators at both [Mater Hospital] and the University of Limerick. Dr Arlene McCurtin Course Director for the SLT programme is the University of Limerick co-ordinator. [Clinical Specialist SLT/Practice Tutor and Senior Speech & Language Therapist/Practice Tutor] are the Mater Hospital co-ordinators.

- This study has been in development since the summer of 2014. Data collection (interviews and focus group) will take place in January/February 2015 and the data will be analysed and written up by May 2015.

What is the study design?

- This study uses a qualitative methodology and use interviews and focus groups to meet participants and ask their opinions. The materials from these interviews is analysed using thematic analysis - the opinion of participants will be organised into themes in order to help better understand the opinions of the participants.

Are there any disadvantages in taking part in this research study?

- There are no disadvantages to taking part or withdrawing.

- Any complaints or concerns should be directed to the Principal Investigator, [Heather Coetzee], SLT Manager Mater Hospital.

What are the possible benefits of taking part?

- The opinions you provide may help speech and language therapists in developing or refining their services to patients undergoing palliative care.

Who approved this study?

- [Mater Hospital Research Ethics Committee] approved this study

What will happen to the results of the research study?

The study results will be used for the following purposes:

- Contribute to the professional qualification degree of the student researchers.
- Presentation/poster at IALP (Dublin) conference August 2016.
- Inform SLT service development with regard to palliative care services.
- Published article.

Interested in taking part in the study?

- If you are interested in taking part in the study, please email [Heather Coetzee, hcoetzee@mater.ie] and we will contact you to arrange a time convenient to you.

- If you do not understand or would like more information please contact the Principal Investigator, [Heather Coetzee], SLT Manager at [hcoetzee@mater.ie] or on [01] 8034107.
Appendix B: Focus group

Introductory script

Introduction

Good morning, thanks for coming, my name is Jemma and this is Rebecca and Ciara. Following a discussion between the hospital’s SLTs and UL, we are carrying out a project on perceptions on the role of speech and language therapists in palliative care. The aim of this focus group is to explore any opinions and perspectives that you may have on the topic. The questions will be broad and there is of course, no right or wrong answer – we really just want your perspectives and all opinions are welcomed.

Hand out forms

So to start, we are handing around the study information sheet. You can have a read of this and ask us any questions about things which you don’t understand or need explaining. Please be aware that all your responses and data will be both confidential and anonymous (i.e. your name will not be used).

Once you have read the information sheet and are happy with that, please read and sign the consent form. The consent form enables you to participate and meets ethical requirements. This is voluntary. You don’t have to, and if you feel you do not want to participate that is your decision and you have the option not to participate. You can also withdraw from the group at any stage.

Lastly, can we ask you to write your first name in capitals on a label and put it on? This will help us when transcribing the data.

Focus Group

So we’ll begin shortly. The focus group will proceed by us putting questions or statements to the group and asking you to share your thoughts and opinions about them. We will act as facilitators to ensure the questions are answered and everyone gets a chance to share their perspectives, if you so choose.

As the group will last around 30-45 minutes, we will be timing the session to make sure all the questions are answered. Ciara will be time keeper and will raise her hand when we need to move onto the next question.

We have also provided you with pens and sticky notepads so you can write down any comments you want to make, either as a reminder to yourself or to give to us after the session so we can add it to the data from the group.

As you can see there are two audio recorders and these will be used to record the session. The data on the tapes will be downloaded to a password protected computer and deleted from the recorders. The data will then be transcribed, anonymised and deleted from the computer. The recorder is used so that no comments are missed.
### Questions

**Focus group questions**

**Q1. Roles**  
Let’s pretend, I don’t know anything about speech and language therapy, could you tell me about the general role of the SLT in the hospital?  
i. How does this general role differ when working with patients receiving palliative care?  
ii. How do you define palliative care?

**Q2. Role development**  
Tell me about role development  
i. How has your role developed in the past decades?  
ii. How do you see it changing in the future?

**Q3. Experiences and Caseload in Palliative Care**  
So let’s talk about the role of the SLT in palliative care  
i. Do you think there is a role?  
ii. What are your experiences of working in this role?  
iii. How much of your caseload involves working with patients receiving palliative care?

**Q4. Service Provision and Withdrawal**  
Tell us about your experience receiving referrals for palliative care patients  
i. Have you ever had a palliative care referral withdrawn?  
ii. How did that make you feel?  
iii. What does referrals being withdrawn say about how other professionals view the role of the SLT in palliative care?
Appendix C: Consent form

CONSENT FORM

Title of Research Study: Perceptions of hospital-based clinical staff on the role of speech & language therapists in palliative care

Participant name:

1. I confirm that I have read and understood the information leaflet dated........ for the above research study and received an explanation of the nature, purpose, duration of the research study and what my involvement will be

2. I have had time to consider whether to take part in this research study. My questions have been answered satisfactorily and I have received a copy of the Information Leaflet

3. I understand that my participation is voluntary (my choice) and that I am free to withdraw at any time up to semi-structured interviews/focus group.

4. I understand that the semi-structured interviews/focus group will be audio recorded with a dictaphone and give my permission for this.

5. I understand my data will be anonymised and deleted after completion of the study.

6. I agree to take part in the above research study

.......................................................... ..........................................................
Name of Participant (in block letters) Date Signature

.......................................................... ..........................................................
Name of Person taking consent Date Signature
(Researcher)
### Appendix D: Focus group summary sheet

**Date:** 26th January 2015

**Facilitators:** Jemma Colclough, Ciara Gleeson and Rebecca Burke

**Research Project:** ‘Perceptions of hospital-based clinical staff of the role of speech & language therapists in palliative care’

<table>
<thead>
<tr>
<th>Trends/Topics</th>
<th>Summary of discussion</th>
</tr>
</thead>
</table>
| 1. Role development                  | - SLTs working in a hospital setting are involved in the assessment and management of speech, voice, receptive and expressive language and swallowing difficulties in an range of adult populations with acute presentations  
- Increased awareness of the role and inclusion of the SLT in the MDT  
- The provision of palliative care for patients is highlighted more and has improved meaning SLTs are more involved |
| 2. Role of the SLT in palliative care | - Important role in dysphagia is recognised  
- Role in communication needs to be developed further and awareness of this area needs to be increased  
- SLTs have a role in educating families and other professionals about their role |
| 3. Caseloads and experiences of palliative care | - Differences between specialties and how they are managed  
- Generally, the caseload percentages were estimated at 50% but is dependent on the specialty and would vary  
- Continuum of palliative care is broader and includes from early diagnosis to end of life and pain management  
- Lack of awareness of the dysphagia management options SLTs can offer |
| 4. Referrals and MDT working         | - Differences between specialties in terms of timing of referral for example early referrals from progressive neurology vs late referrals for patients with dementia  
- Working with the MDT is key for the SLT in palliative care  
- Withdrawal of referrals was highlighted as common  
- Are referrals being withdrawn/not given as SLT cannot offer anything versus are the MDT aware of what SLT can offer?  
- Can receive more/less referrals depending on the doctor’s knowledge of SLT and rotation schedules  
- Very low referrals from certain teams |
| 5. Confidence in role in palliative care | - Uncertainty of stage of patient in palliative care process and what can be offered  
- Limited time frame to implement communication therapy due to large caseloads and patients’ prognosis  
- Lack of clarify and confidence as a profession in palliative care  
- Insufficient training for SLTs for discussing issues concerning death with patients |
Appendix E: Semi-structured interviews

Introductory script

Introduction
Following a discussion between the hospital’s SLTs and UL, we are carrying out a project on perceptions on the role of speech and language therapists in palliative care. The aim of this interview is to explore any opinions and perspectives that you may have on the topic. The questions will be broad and there are no right or wrong answers – we really just want your perspectives and all opinions are welcomed.

Information sheet
You can have a read of this and ask me any questions about things which you don’t understand or need explaining. Please be aware that all your responses and data will be both confidential and anonymous (i.e. your name will not be used).

Consent form
Once you have read the information sheet and are happy with that, please read and sign the consent form. The consent form enables you to participate and meets ethical requirements. This is voluntary. You don’t have to, and if you feel you do not want to participate that is your decision and you have the option not to participate. You can also withdraw from the interview at any stage.

The interview will last 15 minutes at the most
An audio recorder will be used to record the interview. The data on the tapes will be downloaded to a password protected computer and deleted from the recorders. The data will then be transcribed, anonymised and deleted from the computer. The recorder is used so that no comments are missed.

Questions

1. Could you tell me, in your own words, what the SLT does?
   (Probe-What do you think the SLT’s role specifically in hospitals is? And what about communication/dysphagia?).

2. How did you learn about the role of the SLT?
   (Probe-During your qualification or on the job? Do you have much contact with SLTs?)

3. In palliative care, when do you think it is appropriate to refer to SLT and for what reasons?
   (Probe-specific cases? Specific populations?)

4. Are there any cases/situations where you would not make a referral to SLT?
   (Probe- could you elaborate on that a little bit)

5. In a scenario where you have made a referral to SLT, why might you later withdraw the referral?
   (Probe- What's the process involved if you are withdrawing a referral?).
## Appendix F: Thematic networks process example (Palliative considerations)

<table>
<thead>
<tr>
<th>Nodes</th>
<th>Codes</th>
<th>Basic Theme</th>
<th>Organising Theme</th>
<th>Global Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>A question asked a lot: How palliative? It's a grey area It's not really clear to us What exactly do you mean here? Still discovering what it really means to be palliative PC means different things to different people PC-very nebulous It's not an exact science Hard on medical teams Hard on SLTs Months to live-pass away within a week It's tricky Happens more quickly than expected People's conditions change very quickly No set time on end-of-life care</td>
<td>Unclear terminology</td>
<td>Lack of clarity</td>
<td>Evolving Speciality</td>
<td>Palliative Considerations</td>
</tr>
<tr>
<td>Much bigger role Not just end stages SLTs feature more More of an appearance More involved than 5 years ago More involved in counselling More awareness of role Starting to see role Increased awareness SLT role AHPs have bigger profile in hospitals Increased awareness Developing an awareness among the team Should educate teams about SLT role “Look at what I can actually do” Get in early and show them Onus to educate teams: especially in communication Need to identify SLT role Set professional standard Teaching Possible role for SLT Role will develop Role in advocacy Role will expand SLT might be more involved in communication Expand role in dementia SLT role has developed with PC development Whole package given to PC patients Adapting role to PC development</td>
<td>Increased role</td>
<td>Increased awareness</td>
<td>SLT role development</td>
<td></td>
</tr>
</tbody>
</table>
Thoughts for PC changing  
PC highlighted more  
More highlighting person is palliative  
Role of PC has changed  
Now getting in earlier  
Broader continuum  
Maintaining function  
Now not just end-of-life care  
Not just actively dying  
PC changed over last 10 years  
Evolved over time  
Still emerging  
Still discovering PC  
What it really means to be palliative  
Medicine evolving  
Things are shifting  
Things are moving  
Palliative medicine huge now

<table>
<thead>
<tr>
<th>Evolved in recent years</th>
<th>PC development</th>
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<table>
<thead>
<tr>
<th>Not comfortable</th>
<th>Comfort</th>
<th>Quality of life</th>
<th>A holistic approach</th>
<th>Palliative considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good quality, comfort-centred care</td>
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<td>Pain really important</td>
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<td>Symptom management</td>
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<tr>
<td>Person comfortable</td>
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<tr>
<td>Comfort measures</td>
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<tr>
<td>Comfort is key piece</td>
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<tr>
<td>Concerns for discomfort</td>
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<tr>
<td>Solely focus on comfort</td>
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<tr>
<td>Comfort more preferable to treatment</td>
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<tr>
<td>Comfort levels</td>
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<tr>
<td>Prioritise comfort levels</td>
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<tr>
<td>How is comfort perceived?</td>
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<tr>
<td>Dysphagia and communication not seen as symptoms</td>
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<tr>
<td>Dysphagia and communication not seen as having impact on pain</td>
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<tr>
<td>Comfort isn’t always unrestricted diet and fluids</td>
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<tr>
<td>Significant distress</td>
<td></td>
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<tr>
<td>Severe pneumonia</td>
<td></td>
<td></td>
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<tr>
<td>Enjoy food safely</td>
<td></td>
<td></td>
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<tr>
<td>Eating and feeding done safely</td>
<td></td>
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<tr>
<td>Role for SLT in comfort re swallowing?</td>
<td></td>
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<tr>
<td>Coughing and choking on regular fluids</td>
<td></td>
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<tr>
<td>Weighing quality of life vs risk</td>
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<tr>
<td>Balance burden vs benefit for feeding</td>
<td></td>
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<tr>
<td>Prioritise quality of life</td>
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<tr>
<td>Improve quality of life</td>
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<tr>
<td>Patient-devastated</td>
<td></td>
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<tr>
<td>Patient-centred care</td>
<td></td>
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<tr>
<td>Wanted to say so much</td>
<td></td>
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<tr>
<td>Making them happy</td>
<td></td>
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</tr>
</tbody>
</table>

<p>| Safe feeding: balancing act |                     |
| Patient-centred |                     |</p>
<table>
<thead>
<tr>
<th>Optimising their last time</th>
<th>Family prioritising their last time</th>
<th>Person can say their wishes for end of life care</th>
<th>Quality of life is key piece</th>
<th>End of life- people need quiet</th>
<th>End of life- need time to get used to it</th>
</tr>
</thead>
<tbody>
<tr>
<td>Documenting family wishes</td>
<td>Family wish comfort to be priority</td>
<td>Family meeting</td>
<td>Family discussion</td>
<td>Handing-over decision making to family</td>
<td>Family-SLT input may not be appropriate</td>
</tr>
<tr>
<td>Family wish comfort to be priority</td>
<td>Family meeting</td>
<td>Family discussion</td>
<td>Handing-over decision making to family</td>
<td>Family-SLT input may not be appropriate</td>
<td>Family choose diet</td>
</tr>
<tr>
<td>Don’t want to be interrupted</td>
<td>It’s all about the family</td>
<td>No interruptions-by lots of different people</td>
<td>Patient-“Please leave me alone”</td>
<td>End of life- “What’s the point?”</td>
<td>Different patient attitudes</td>
</tr>
<tr>
<td>Patient may decide- no SLT</td>
<td>Patient wants hospice</td>
<td>Tapered to each individual</td>
<td>Basing decisions case by case</td>
<td>Every case is individual</td>
<td>Every case needs to be discussed</td>
</tr>
<tr>
<td>Family wishes</td>
<td>Choice</td>
<td>A holistic approach</td>
<td>Palliative considerations</td>
<td>Family wishes</td>
<td>Family time prioritised</td>
</tr>
</tbody>
</table>
Appendix G: Word cloud
### Appendix H: Quotations in results

<table>
<thead>
<tr>
<th>Quotation</th>
<th>Node</th>
<th>Code</th>
<th>Basic theme</th>
<th>Organising theme</th>
<th>Global theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>“We are mostly called upon for swallow management” (SLT 1)</td>
<td>Mostly swallow management</td>
<td>Referrals mainly for swallow</td>
<td>Mainly dysphagia</td>
<td>Current role</td>
<td>Role of SLT in palliative care</td>
</tr>
<tr>
<td>“It’s very much dysphagia rather than communication” (HCS 4)</td>
<td>Prioritisation of dysphagia</td>
<td>Dysphagia input more important than communication</td>
<td>Mainly dysphagia</td>
<td>Current role</td>
<td>Role of SLT in palliative care</td>
</tr>
<tr>
<td>“When people are very near the end of their final journey there would be no need for SLT services in relation to communication” (HCS 8)</td>
<td>No need for communication when actively dying</td>
<td>Lack of communication referrals</td>
<td>Less communication</td>
<td>Current role</td>
<td>No need for communication when actively dying</td>
</tr>
<tr>
<td>“I know there’s been studies... of our role and I don’t think that’s fully implemented in terms of communication” (SLT 6)</td>
<td>Big role not implemented</td>
<td>Lack of communication referrals</td>
<td>Less communication</td>
<td>Current role</td>
<td>Role of SLT in palliative care</td>
</tr>
<tr>
<td>“They may not need to see the person themselves but they may need to see the family members because the family members get very distressed” (HCS 8)</td>
<td>Working with families Distressed families</td>
<td>Indirect work with the family</td>
<td>Indirect work</td>
<td>Current role</td>
<td>Role of SLT in palliative care</td>
</tr>
<tr>
<td>“Speech and language therapy is very highly respected within the hospital” (HCS 3)</td>
<td>SLT highly respected in hospital</td>
<td>MDT see SLT role as valuable</td>
<td>Respect</td>
<td>Team working</td>
<td>Role of SLT in palliative care</td>
</tr>
<tr>
<td>“I’ve gleaned a lot from the team” (SLT 1)</td>
<td>Gleaned a lot from the team</td>
<td>Learning from each other</td>
<td>Importance of MDT approach</td>
<td>Team working</td>
<td>Role of SLT in palliative care</td>
</tr>
<tr>
<td>“You really need them (MDT)” (SLT 4)</td>
<td>Need MDT</td>
<td>Learning from each other</td>
<td>Importance of MDT approach</td>
<td>Team working</td>
<td>Role of SLT in palliative care</td>
</tr>
<tr>
<td>“It’s not just about sending out the referral; we engage, we talk” (HCS 8)</td>
<td>We engage We talk</td>
<td>Communication between team members is key</td>
<td>Importance of MDT approach</td>
<td>Team working</td>
<td>Role of SLT in palliative care</td>
</tr>
<tr>
<td>“When you have an MDT focused approach, the (SLT) role is important, it’s understood, and it’s appreciated. If you don’t have an MDT approach then it’s a little bit more haphazard” (HCS 6)</td>
<td>Need MDT approach to understand role</td>
<td>Efficient MDT approach needed to understand SLT role</td>
<td>Importance of MDT approach</td>
<td>Team working</td>
<td>Role of SLT in palliative care</td>
</tr>
<tr>
<td>“Am I just interfering and causing more problems?” (SLT 4)</td>
<td>Interfering Causing problems?</td>
<td>Fear of being intrusive</td>
<td>Confidence</td>
<td>Challenges</td>
<td>Role of SLT in palliative care</td>
</tr>
<tr>
<td>“I’m not sure what I can offer a lot of the time...” (SLT 5)</td>
<td>Not confidence in what SLT can offer</td>
<td>SLTs uncertain about what they can offer</td>
<td>Confidence</td>
<td>Challenges</td>
<td>Role of SLT in palliative care</td>
</tr>
<tr>
<td>“I think it’s a gap in even undergraduate training...of how to talk about things like that with patients” (SLT SLT 1),</td>
<td>Gap in undergraduate training</td>
<td>No specific SLT palliative care training</td>
<td>Training</td>
<td>Challenges</td>
<td>Role of SLT in palliative care</td>
</tr>
<tr>
<td>“So we’re making these very informed and holistic decisions” “In a setting where we don’t know if those will be carried out”(SLT 1)</td>
<td>Don’t know if care will be continued</td>
<td>Lack of continuity between services</td>
<td>Hospital-working</td>
<td>Challenges</td>
<td>Role of SLT in palliative care</td>
</tr>
<tr>
<td>“It’s not just actively dying” (HCS 1)</td>
<td>Now not just end-of-life care</td>
<td>Evolved in recent years</td>
<td>Palliative care development</td>
<td>Evolving speciality</td>
<td>Palliative considerations</td>
</tr>
<tr>
<td>“The continuum is much broader now” (SLT 2)</td>
<td>Broader continuum</td>
<td>Evolved in recent years</td>
<td>Palliative care development</td>
<td>Evolving speciality</td>
<td>Palliative considerations</td>
</tr>
<tr>
<td>“it’s still emerging and we’re still discovering what it really means to be palliative or to be at the end of your life” (SLT 1)</td>
<td>Still discovering what it really means to be palliative</td>
<td>Still emerging</td>
<td>Palliative care development</td>
<td>Evolving speciality</td>
<td>Palliative considerations</td>
</tr>
<tr>
<td>“nebulous” (HCS 8)</td>
<td>Palliative care: very nebulous</td>
<td>Unclear terminology</td>
<td>Lack of clarity</td>
<td>Evolving speciality</td>
<td>Palliative considerations</td>
</tr>
<tr>
<td>“grey area” (SLT 4)</td>
<td>Grey area</td>
<td>Unclear terminology</td>
<td>Lack of clarity</td>
<td>Evolving speciality</td>
<td>Palliative considerations</td>
</tr>
<tr>
<td>“You find yourself asking “how palliative?”” (SLT 1)</td>
<td>A question asked a lot: How palliative?</td>
<td>Unclear terminology</td>
<td>Lack of clarity</td>
<td>Evolving speciality</td>
<td>Palliative considerations</td>
</tr>
<tr>
<td>“we do have an onus to educate teams, especially in communication” (SLT 2)</td>
<td>Educate teams about role</td>
<td>Need to increase role in education</td>
<td>SLT role development</td>
<td>Evolving speciality</td>
<td>Palliative considerations</td>
</tr>
<tr>
<td>“We need to identify what that role is specifically as a group of therapists and as a professional standard first” (SLT 5)</td>
<td>Need to identify SLT role Set professional standards</td>
<td>Future development</td>
<td>SLT role development</td>
<td>Evolving speciality</td>
<td>Palliative considerations</td>
</tr>
<tr>
<td>“Poor understanding that comfort doesn’t always mean eating and drinking whatever you like” (SLT1)</td>
<td>comfort isn’t always unrestricted diet and fluids</td>
<td>Comfort</td>
<td>Quality of life</td>
<td>A holistic approach</td>
<td>Palliative considerations</td>
</tr>
<tr>
<td>“That patient I worked with was so devastated and had so much she wanted to say to her family” (SLT 2)</td>
<td>Patient-Devastated Wanted to say so much</td>
<td>A holistic approach</td>
<td>Quality of life</td>
<td>A holistic approach</td>
<td>Palliative considerations</td>
</tr>
<tr>
<td>“While you do feel as if you’re doing something beneficial to improve the comfort and quality of life...you don’t know how that is being construed or perceived by family” (SLT 1)</td>
<td>Improve quality of life How is comfort perceived?</td>
<td>A holistic approach</td>
<td>Quality of life</td>
<td>A holistic approach</td>
<td>Palliative considerations</td>
</tr>
<tr>
<td>“It’s all about family, it’s all about people being there and not being interrupted too much by lots of different people” (7)</td>
<td>It’s all about family No interruptions by lots of different people being there</td>
<td>Family time prioritised</td>
<td>Quality of life</td>
<td>A holistic approach</td>
<td>Palliative considerations</td>
</tr>
<tr>
<td>“Certain teams in the hospital will refer... but other teams are more unsure” (SLT 3)</td>
<td>More referrals from certain teams</td>
<td>More referrals from certain teams</td>
<td>Prognosis</td>
<td>Specific factors</td>
<td>Referral matters</td>
</tr>
<tr>
<td>“Sometimes in palliative care people’s conditions change very quickly” (HCS 7)</td>
<td>Changing conditions</td>
<td>Changing conditions</td>
<td>Prognosis</td>
<td>Specific factors</td>
<td>Referral matters</td>
</tr>
<tr>
<td>“important to refer early” (HCS 2)</td>
<td>Importance of early referral</td>
<td>Benefits of early referral</td>
<td>Timing</td>
<td>Specific factors</td>
<td>Referral matters</td>
</tr>
<tr>
<td>“happens a lot” (SLT 4)</td>
<td>Happens a lot</td>
<td>Lack of agreement over occurrence</td>
<td>Withdrawal</td>
<td>Barriers to access</td>
<td>Referral matters</td>
</tr>
<tr>
<td>“blanket no” (SLT 4)</td>
<td>Blanket no</td>
<td>Medical team says ‘no’</td>
<td>Withdrawal</td>
<td>Barriers to access</td>
<td>Referral matters</td>
</tr>
<tr>
<td>“Minimum intervention of what absolutely needs to be done” (HCS 3)</td>
<td>Minimum intervention</td>
<td>Minimum input</td>
<td>Withdrawal</td>
<td>Barriers to access</td>
<td>Referral matters</td>
</tr>
<tr>
<td>“you don’t need to go near them” (SLT 4)</td>
<td>You don’t need to go near them</td>
<td>Medical team says ‘no’</td>
<td>Withdrawal</td>
<td>Barriers to access</td>
<td>Referral matters</td>
</tr>
<tr>
<td>“it can be the opposite of the team wanting to withdraw the referral” (SLT 3)</td>
<td>Opposite of team withdrawing referral</td>
<td>Lack of agreement over occurrence</td>
<td>Withdrawal</td>
<td>Barriers to access</td>
<td>Referral matters</td>
</tr>
<tr>
<td>“if you felt you really had a role it wouldn’t be difficult to push for” (SLT 1)</td>
<td>Could push for role</td>
<td>Lack of agreement over occurrence</td>
<td>Withdrawal</td>
<td>Barriers to access</td>
<td>Referral matters</td>
</tr>
</tbody>
</table>
“We might have someone who knows loads about what speech therapists do and have to offer...so then we get loads of referrals for that 6 months...when that person moves out we might have someone who has less experience...and less awareness of what we see our role as....and then (the number of referrals) wanes off again” (SLT 3)

<table>
<thead>
<tr>
<th>Dependent on individuals knowledge</th>
<th>Knowing when to refer</th>
<th>Conflicting perceptions</th>
<th>Barriers to access</th>
<th>Referral matters</th>
</tr>
</thead>
</table>

They would generate us minimal referrals...that surprises me because I would have thought they'd be well placed to generate a referral” (SLT 1)

<table>
<thead>
<tr>
<th>Surprise at lack of referral</th>
<th>Knowing when to refer</th>
<th>Conflicting perceptions</th>
<th>Barriers to access</th>
<th>Referral matters</th>
</tr>
</thead>
</table>

“I don't think they have that knowledge that we do more than just modify (liquids)” (SLT 2)

<table>
<thead>
<tr>
<th>Poor understanding-modify</th>
<th>Poor understanding of role</th>
<th>Conflicting perceptions</th>
<th>Barriers to access</th>
<th>Referral matters</th>
</tr>
</thead>
</table>

“From the MDT’s perspective I think they’ve probably poor understanding of our role in terms of communication” (SLT 2)

<table>
<thead>
<tr>
<th>Lack of knowledge regarding communication</th>
<th>Poor understanding of role</th>
<th>Conflicting perceptions</th>
<th>Barriers to access</th>
<th>Referral matters</th>
</tr>
</thead>
</table>

“It was something I’d never considered before to be honest with you” (HCS 3)

<table>
<thead>
<tr>
<th>Never considered before</th>
<th>SLT not primarily considered in palliative care</th>
<th>Conflicting perceptions</th>
<th>Barriers to access</th>
<th>Referral matters</th>
</tr>
</thead>
</table>

“There is a need for SLT involvement to end of life” (HCS 6)

<table>
<thead>
<tr>
<th>Role from admittance to end of life</th>
<th>Role at end of life</th>
<th>Conflicting perceptions</th>
<th>Barriers to access</th>
<th>Referral matters</th>
</tr>
</thead>
</table>

“I do think SLTs have a role in palliative care but maybe not so for the patient in the later stages” (HCS 8)

<table>
<thead>
<tr>
<th>Not at later stages</th>
<th>Not a useful resource at end of life</th>
<th>Conflicting perceptions</th>
<th>Barriers to access</th>
<th>Referral matters</th>
</tr>
</thead>
</table>