



UNIVERSITY *of* LIMERICK

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

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Word count: 7,452

Intended Journal of submission: Journal of Palliative Medicine

A research project submitted to the Department of Speech and Language Therapy as partial fulfilment of the MSc in Speech and Language Therapy

“You matter because you’re you, and you matter to the end of your life. We will do all we can not only to help you to die peacefully, but also to live until you die.” (Dame Cicely Saunders)

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Acknowledgements

Firstly, I would like to sincerely thank my supervisor Dr. Arlene McCurtin. Her guidance, support, encouragement and advice were invaluable throughout the project.

Thank you to my research colleagues Ciara and Jemma for making research fun. We made it!

To all those who participated in this study, your participation has been greatly appreciated. Thank you also to our gatekeeper in the hospital for their help in recruiting participants.

To Peter; thank you for your continuous moral support, patience and most importantly for the proof reading!

Finally, I would like to thank my family; Mum, Christina and Robert, for their unwavering support throughout the whole masters but especially in this final semester.

Dad, I had to do this one without you and so I dedicate this third (and last!) dissertation to you. Thank you for teaching me that determination and hard work pay off.

“When you feel like giving up, go back and do it one more time” Tommy Burke

Abstract

Background

Palliative care is defined as the active holistic care of patients with advanced progressive illnesses (National Institute for Clinical Excellence; NICE 2004). In recent years, speech and language therapists (SLTs) have become involved in palliative care; from both communication and dysphagia perspectives (Sharp *et al* 2006). However, the role of SLTs in this area is currently unclear, poorly defined and under researched (Pollens 2012). Considering the increasing concentration on palliative care services and the recency of SLT intervention in this area, it is timely to gain an integrated overview of the role of hospital-based SLTs in palliative care.

Aim

To examine the perceptions of the role of the SLT in palliative care from the perspectives of hospital staff who tend to be the primary referral sources and also the SLTs who provide such services.

Methods

An acute hospital identified an issue with withdrawal of referrals to SLT. Participants were recruited from this hospital via a Senior SLT, who acted as gatekeeper. Data collection took place on site in the hospital. Ethical approval was obtained. One focus group was run with seven SLTs. Eight semi-structured individual interviews took place with hospital clinical staff including doctors, nurses, medical social workers and a dietician who are primary referrers to SLT. Data was transcribed, anonymised and analysed using thematic network analysis (Attride-Stirling 2001).

Results

Three key themes were identified; SLT role in palliative care, Referral matters and Palliative considerations. Findings reflect the complex nature of SLTs working in palliative care. The SLT scope of practice is largely dysphagia based with a need for more communication work highlighted. SLTs face challenges in their role which include working in a hospital setting, a lack of training and a lack of confidence. Referrals are affected by the patient's prognosis and varying levels of knowledge of the SLT role by team members.

Palliative medicine as a speciality has evolved with quality of life and choice the key constructs for patient-centred care.

Conclusions

The expansion of palliative medicine has led to an increase in demand for SLT services. Role development at a professional level with specific training for SLTs working in palliative care would increase confidence in the area. Additionally, interdisciplinary discussion between teams would further increase awareness of the role of the SLT in palliative care. In particular, the importance of communication at end of life needs addressing in order to improve service provision for palliative patients.

Keywords

Palliative care, speech and language therapy, role, perception, hospital-based clinical staff.

1. Introduction

Palliative care is an important and developing area of care within the health services. As speech and language therapists (SLTs) work in the areas of communication and dysphagia (swallowing and eating problems), they can receive referrals for patients who are in receipt of palliative care services. Speech and language intervention is a relatively new contribution to palliative care and currently the role of SLTs in this area is unclear and poorly defined (Pollens 2012). This section will explore; palliative care services and what constitutes the role of the SLT in palliative care.

1.1 Palliative care

The World Health Organisation (WHO 2002) defines palliative care as the active care of patients whose disease is not responsive to curative treatment, with its goal to achieve the best quality of life for patients and their families (NICE 2004). In order to achieve this goal six main components of palliative care are outlined;

1. Affirms life and regards dying as a normal process
2. Neither hastens nor postpones death
3. Provides relief from pain and other distressing symptoms
4. Integrates the psychological and the spiritual aspects of care
5. Offers a support system to help patients live as actively as possible until death
6. Offers a support system to help the family cope during the patient's illness and in their own bereavement (WHO 2002).

The concept of palliative care is relatively new and in 1995, Ireland became the second country in Europe to recognise palliative medicine as a medical specialty in itself (Joint Committee on Health and Children 2014). Since 2001, Irish health policy has advocated that palliative care services should be available to all people in all settings including acute hospitals, hospice settings and at home (Irish Hospice Foundation and Health Service Executive; IHF and HSE 2008). Palliative care services are now advocated for patients with progressive illnesses from diagnosis until death as well as those with cancer (Department of Health 2008).

Ireland has the fastest rising need for palliative care in Europe due to its rapidly ageing population (Kane *et al* 2015). There were over half a million people aged over 65 in 2011

(Joint Committee on Health and Children 2014) and in thirty years that number is estimated to reach 1.4 million (IHF 2013). Current data reveals annually, 80% of deaths in Ireland are from conditions considered to have palliative care needs (Kane *et al* 2015). These figures serve to illustrate the growing need for well-developed palliative care services in Ireland. Irish policy advocates a team approach in palliative care, in which SLTs are part of the allied health professional (AHP) group (Department of Health and Children 2001).

1.2 SLT role in palliative care

Tomblin and Mueller (2012) outline that SLTs' "knowledge of feeding, swallowing, cognition and communication make them uniquely qualified to work in the area of palliative care" (p.109). Indeed, in recent years SLTs have become involved in palliative care from both dysphagia and communication perspectives (Sharp *et al* 2006). Dysphagia is often a pivotal issue in palliative care (Pollens 2012) and is usually the primary reason for a referral to SLT in hospital settings (Groher and Groher 2012).

The aim of dysphagia management may be to reduce the risk of aspiration, dehydration or malnutrition but there is also an emphasis on comfort and choice in palliative care (Pollens 2004). The promotion of choice becomes pertinent in palliative care when considerations such as nil by mouth (NPO) or non-oral feeding come into play. If a patient chooses against non-oral feeding, the SLT can provide clinical instructions to minimise the possible complications of oral feeding, for example, reducing bolus size or slower pacing to allow time for an extra swallow (Pollens 2004). The SLT role in dysphagia supports the third component of palliative care – provides relief from pain and other distressing symptoms (WHO 2002). Eating at the end of life stage may no longer be for nutritional purposes and fundamentally the SLT can assist in developing strategies that maximise the patient's ability to experience the pleasure of eating (Pollens 2004).

Communication is a vital role for SLTs in the broad sense but especially in palliative care (Salt *et al* 1999). Quality of life, the core principle of palliative care (NICE 2004) is supported when a patient is able to communicate wishes, needs and feelings as well as maintain relationships (Pollens 2012). Specifically, SLTs can introduce strategies to support communication and enhance its effectiveness (Pollens 2004). The importance of

optimising communication is supported by the fifth component of palliative care – offers a support system to help patients live as actively as possible until death (WHO 2002). In order to achieve this it is imperative to encourage social connectivity and closeness between patients and caregivers (Pollens 2004) particularly as communication difficulties may impact on overall emotional well-being. A further element to the SLTs role may be to consult or provide information and advice to patients, families and members of the palliative care team in relation to communication, cognition and swallowing function (Pollens 2004).

Contributing to the holistic care of the patient is another role for SLTs in palliative care as highlighted by Pollens (2004). This may be achieved by enhancing the patient's communication environment and training family members, carers and the palliative team members in communication facilitation (Eckman and Roe 2005). Interestingly, Lobb *et al* (2006) highlighted that depression and anxiety are almost as common among caregivers as among patients themselves. As the sixth component of palliative care focuses on offering a support system to help families cope (WHO 2002), it is necessary for SLTs to consider how they might support the family as well as the patient.

Despite the aforementioned proposal by Pollens (2004), it is still widely agreed that there is an overall lack of clarity on the role of the SLT in palliative care (Salt *et al* 1999; Eckman and Roe 2005; Toner and Shadden 2012). Toner and Shadden (2012) suggest this may be in part due to the perception that SLTs have a limited role when improvement of function is not expected. It may also be attributed to the fact that there is an overall lack of robust research studies on the role of the SLT in palliative care (Toner and Shadden 2012). The majority of studies including those discussed in this review are review studies which in some cases (for example Pollens 2004, Pollens 2012) are largely based on the opinions of the author. This means that in terms of the evidence base, this is an area which is underdeveloped and requires extensive further research which can in turn inform service development and innovative practice (Roe and Leslie 2010). It is also worth noting that the Irish Association of Speech and Language Therapists (IASLT) have no specific statements or information relating to the SLT role in palliative care.

1.3 Collaborative working in palliative care

Interdisciplinary working is vital in providing the best services to patients. In terms of Irish policy, it is advised to have locally agreed guidelines, clear ethics and duties that underpin working palliative strategies (IHF and HSE 2008). It is proposed that SLTs should work within a multi-disciplinary team (MDT) where there is a mutual awareness of roles (Roe and Leslie 2010). However, in a study of 75 AHPs including SLTs, it was highlighted that limited awareness by other professionals of the specific role of AHPs was a significant barrier which impacted on access to services and compromised patient care (Thomson *et al* 2006). As most patients access SLT services via referral by other health professionals, (Allied Health Professions Palliative Care Project Team 2004) this would appear to be a major barrier for collaborative working in palliative care.

Another issue apparently affecting collaborative working is an uncertainty about when to refer to SLT as highlighted by Pollens (2012). Supporting this is Faithfull *et al* (2005) who examined service use in palliative care patients with malignant brain tumours. It was found that out of 39 patients only 8 accessed SLT services despite 25 patients having difficulties with communication or dysphagia. Similarly in terms of role perception, Cruikshank and Wilkinson (1998) identified that SLTs felt carers and patients had a limited understanding of what they could offer. Even though SLT role awareness may have developed considerably since 1998, it is still a concerning finding given that communication, cognition and swallowing difficulties affect the quality of life for palliative care patients (Pollens 2012).

1.4 Importance of current research

Considering the growing need for good quality, patient centred palliative care services in Ireland, the recency of speech and language intervention in this area and the uncertainty of referral to SLT, it is worth asking the question; how is the SLT role in palliative care perceived? To this end, this study examined the perceptions of the role of the SLT in palliative care from the perspectives of hospital staff who tend to be the primary referral sources and also the SLTs who provide such services.

2. Methods

This section outlines the methodology undertaken during the study.

2.1 Study design

This research originated in response to a particular concern in an acute hospital setting on the withdrawal of referrals to SLT services in palliative care. Therefore, the aims of this study are to;

- Explore hospital-based SLTs' interpretation of their role in palliative care.
- Explore hospital-based palliative care providers' interpretation of SLTs role in palliative care.
- Present an integrated overview on the understandings of the role of the hospital based SLT in palliative care.

This study adopted a qualitative methodology with a combination approach of focus groups and individual interviews. A focus group was chosen to collect data from SLTs working in the acute hospital setting so that a range of opinions and an overall collective view could be obtained. Completing semi-structured interviews was a convenient means of collecting data from a diverse group of hospital clinical staff (HCS).

2.2 Participants

For the purpose of the study, convenience sampling was used to identify and recruit participants from the acute hospital setting. The inclusionary criteria were;

- HCS who refer patients receiving palliative care for SLT management and
- Hospital SLTs that may or may not be involved in palliative care services.

A Senior SLT, acting as gatekeeper, circulated the study information leaflet and consent forms (see Appendix A and B) to potential participants via email. Participants were then contacted by the researchers to arrange a convenient time for interviews to take place. Fifteen participants were recruited. Seven SLTs participated in the focus group and eight HCS participated in individual semi-structured interviews including doctors, nurses, medical social workers and a dietician. The total number of participants reflects on the minimum number of participants typically required to support qualitative methodologies (Saldana 2013).

2.3 Procedures

Data collection took place on site in the acute hospital to increase the convenience for the participants. The same procedures were used for both data collection types to account for rigour and reliability of findings.

2.3.1 Focus group

The focus group with the SLTs was conducted by three researchers and lasted 45 minutes in length. Informed consent was obtained before commencement of the focus group. One researcher led the group with pre-set questions and probed participants as necessary. The second researcher's role was time keeping, which ultimately ensured a smooth process and sufficient time for all questions to be answered. The third researcher acted as scribe. Group dynamics including social norms and peer influence are recognised limitations of focus group methodologies (Neergaard *et al* 2009). However, such methodologies allow for a wide range of opinions and views to be collected and are useful for under-researched areas of SLT (Braun and Clarke 2006).

2.3.2 Semi-structured individual interviews

The three researchers conducted several of the 8 individual interviews with HCS. Each interview was led by one researcher and the mean length was 10 minutes. Informed consent was obtained before commencement of the interviews and participants were assured of their anonymity. It is important to recognise the limitations of interviews as a qualitative methodology. For example; 'the interviewer effect' where participants respond differently depending on how they perceive the interviewer (Denscombe 2007) and 'demand characteristics' where responses are influenced by what the participant thinks the situation requires (Gomm 2004). The aforementioned issues were particularly relevant for this study as the interviewers were SLT students and participants were responding to questions on the SLT role in the hospital. Nonetheless, the cooperative nature of interviews allows for disclosure of thoughts and feelings leading to a rich, invaluable quality to data collection (Gomm 2004).

2.4 Materials

Two digital audio recorders (main and backup) were utilised. A script was devised to ensure a clear structure for the focus group and individual interviews. This allowed for a

cohesive and consistent format. The same question format was used for the focus group and the individual interviews so that there was limited variance in the main stimulus questions (see Appendix C).

2.5 Ethics

This study was approved by both the University of Limerick Ethics Committee and the Hospital's Research Ethics Committee.

2.6 Data analysis

Data was transcribed, anonymised and analysed using thematic network analysis (Attride-Stirling 2001). Thematic network analysis is a robust and highly sensitive tool for the systematisation and presentation of qualitative analyses (Attride-Stirling 2001). An initial iterative analysis of data from the focus group and individual interviews identified preliminary nodes, codes and then themes further sub divided into basic, organising and global themes (see Appendix D for an example of the analysis process). Saldana (2003) identifies 'interrelationship' as the examination of possible influences and affects within, between and among data. At this stage of analysis, the data was therefore combined in order to obtain an integrated perspective of all clinical staff's opinions.

Lincoln and Guba (1985) refer to credibility, transferability, dependability and confirmability as the key constructs required when assessing quality in qualitative studies. To adhere to these constructs a number of specific strategies were used to ensure rigour and representativeness including;

- Immersion of the researchers in the data prior to transcription and analysis.
- Each stage of analysis was documented and data clearly assigned or reassigned to codes at each stage.
- Mind maps were utilised to show the development of coding.
- To determine the reliability of codes (Anderson and Felsenfeld 2003), an independent third party was provided with a list of codes and basic themes. They were asked to place each code beside the basic theme felt most appropriate. Agreement was achieved for 7 out of 10 codes which confirmed the validity of coding.

- Member checking was utilised for the focus group to confirm the validity of recorded data and preliminary interpretations (see Appendix E). Member checking was not deemed necessary for the interviews due to their short and individual nature.
- Transcriptions were checked by a second listener to account for sections which were unintelligible.
- Wordle.com was used to check for consistency of codes.

Table 1 outlines the steps undertaken during the data analysis stage;

Table 1: Data analysis steps	
1. Transcription and anonymisation of data	
2. Initial noding	
3. Coding framework devised	
4. Codes grouped into categories	
5. Thematic networks constructed	
	<ul style="list-style-type: none"> ▪ Basic themes selected ▪ Rearranged into organising themes ▪ Global themes deduced
6. Thematic networks illustrated	
7. Verified and refined the networks	

3. Results

This section outlines the results from the study.

3.1 Sample

In total, fifteen participants took part in the study. Table 2 below outlines the sample demographics. Participants were allocated pseudonyms to preserve their anonymity and these have been used in reporting the findings.

Table 2: Sample demographics			
SLTs	Gender	Hospital clinical staff	Gender
Senior SLT	Female	Doctor	Female
Senior SLT	Female	Doctor	Female
Senior SLT	Female	Nurse	Female
Senior SLT	Female	Nurse	Female
Senior SLT	Female	Medical social worker	Female
Senior SLT	Female	Medical social worker	Female
Basic grade SLT	Female	Medical social worker	Female
-	-	Dietician	Female

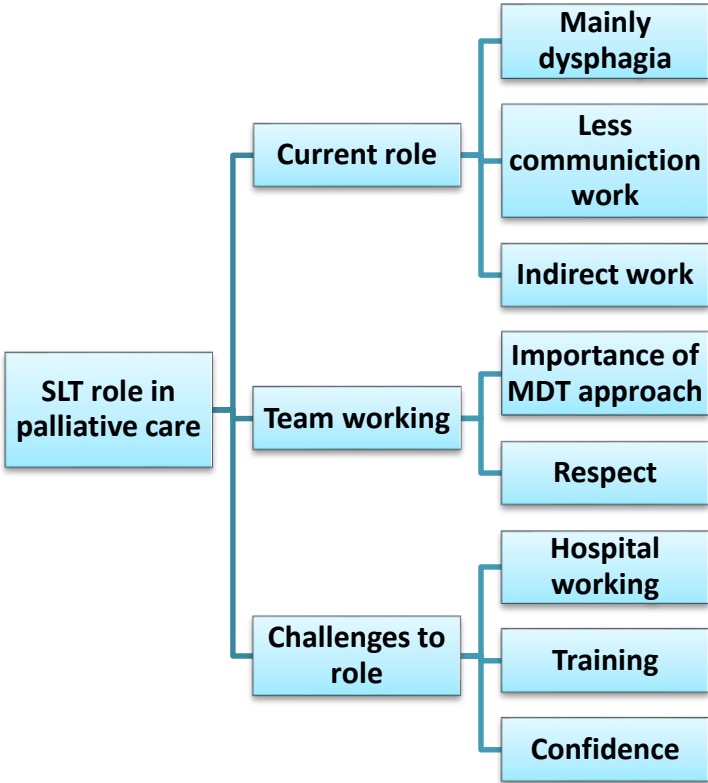
3.2 Themes

The themes that emerged from the data reflect the complex nature of SLTs working in palliative care. The three global themes are; SLT role in palliative care, Referral matters and Palliative considerations. Overall, large similarities emerged from the two data sets (the focus group and individual interviews), but important differences are represented.

3.3 Theme 1: SLT role in palliative care

This theme encompasses the SLT role in palliative care which includes current practices, the importance of team working and the challenges SLTs face in this role. Figure 1 below illustrates theme 1 including organising and basic themes.

Figure 1: Theme 1: SLT role in palliative care



3.3.1 Current role

Indirect working was a concept encapsulated throughout the study by both SLTs and HCS. SLTs felt a large part of their role in palliative care was indirect work. *‘It was a lot of indirect work with the family’* said (Emma, SLT) and *‘building relationships with families’* was a component of this (Tracy, SLT). Similarly, Julie (SLT) highlighted *‘a lot of my management would be dealing with the team, not dealing directly with the patient’*. Consultation also encompassed indirect working where Catherine (SLT) says:

‘A consult and then coming back out again not necessarily being involved in the rest of the patient’s care’.

HCS also highlighted indirect referrals to SLT *‘for advice’*, *‘frequently occurs’* (Mary, HCS). A counselling and support role was also highlighted by SLTs due to the nature of their work and because *‘we really give patients time to communicate’* (Alison, SLT).

SLTs emphasised the majority of their role in palliative care is dysphagia based and referrals from HCS are largely for dysphagia. This was supported by HCS with Sarah saying

their involvement with SLT *'is more swallowing, than communication'*. Diet modification, risk management, comfort measures and maintaining a functional swallow were all components emphasised for dysphagia input in palliative care. In particular *'balancing the burden versus the benefit'* of eating and *'weighing quality of life versus risk'* (Alison, SLT) were key constructs. SLTs were seen to have an important input for *'difficult decisions'* (Mary, HCS). Deirdre (HCS) explained:

'Do we allow the patient fluid and diet with risk or do we withhold it because there's an aspiration risk?'

In terms of communication, SLTs highlighted they have a role in facilitating communication and the use of communication strategies, for example *'visual aids'* (Tracy, SLT) *'memory books'* (Julie, SLT) and *'sourcing AAC devices'* (Tracy, SLT). The communication role was emphasised as vital by both SLTs; *'I had a huge role in terms of facilitating communication and using AAC, a really valuable role'* (Zoe, SLT) and also by HCS *'it's important for patients and families, the communication side of things'* (Mary, HCS). SLTs outlined *'there's a big role for role development in communication'* (Vicky, SLT) but a barrier to this is *'the team don't realise how much we can offer from a communication point of view'* (Catherine, SLT). Similarly, Tracy (SLT) says:

'From the MDTs perspective I think they've probably a poor understanding of our role in terms of communication'.

Lack of understanding of the communication role was mentioned by some HCS, for example; *'I don't really know what the speech and language therapist does in communication maybe because I haven't really focused on it and it's not my area of expertise'* (Suzanne, HCS). In contrast, other HCS felt they utilised SLT services for communication input often; *'communication, very definitely we would need help a lot of the time'* (Kate, HCS).

3.3.2 Team working

SLTs and HCS emphasised the importance of an MDT approach in palliative care in which communication between team members is key. SLTs highlighted that *'SLTs have increased inclusion in multi-disciplinary team meetings'* (Alison, SLT). Emma (SLT) says *'I've gleaned*

a lot from the team' and *'you really need the MDT'* (Julie, SLT). SLTs also highlighted the importance of the MDT approach for understanding the SLT role especially in *'showing the team what we can do'* (Tracy, SLT). Zoe (SLT) also says *'you're able to say to them look this is what we do'*. Specifically HCS emphasised *'learning together and from each other'* (Charlotte, HCS) is important. Kate (HCS) says:

'It was good to joint work and I think it was ensuring the best practice, the best outcome for the patient'.

Respect emerged as a key construct within team working specifically HCS' respect for SLTs. *'I think SLT is very highly respected within the hospital'* (Mary, HCS) and *'SLT input is hugely valuable for the patient'* (Sarah, HCS). Also mentioned was that SLTs are seen as high in the AHP hierarchy and *'staff trust SLT decisions'* (Mary, HCS).

3.3.3 Challenges to role

This sub theme illustrates the main challenges for SLTs working in palliative care. The issue of confidence was quite evident during the focus group. Specifically, SLTs feel *'out of depth in counselling role'* (Zoe, SLT) and *'conversations about dying'* are frequent says Tracy (SLT). Intrusiveness and fear were also common components; *'afraid of being intrusive'* says Catherine (SLT) and *'am I a nuisance around here, what am I doing?'* (Alison, SLT). The issue of uncertainty of what SLT can offer also emerged with Vicky (SLT) saying *'I'm not sure what I can offer a lot of the time'*. Additionally, Zoe (SLT) says *'Am I just interfering and causing more problems?'*

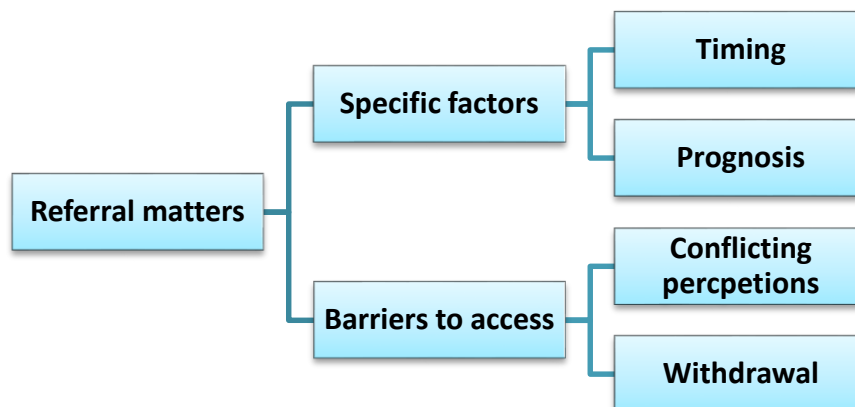
Central to this is the issue of lack of training. Firstly, SLTs highlighted there is no specific training for SLTs working in palliative care. Vicky (SLT) adds *'I think that's a gap in even undergraduate training; how to talk about things like that with patients'*. Alison (SLT) expresses palliative care working *'needs to be addressed at an undergraduate level for speech therapists'*. Secondly, all HCS said they received no training about the SLT role during their qualification and only came across SLT on the job in the hospital. Deirdre (HCS) says *'we certainly didn't spend any time with speech and language therapists in our training'* or Jane (HCS) *'I actually don't know if I ever heard of the word speech therapist during my training'*.

Service constraints in terms of working in a hospital were issues for SLTs working in palliative care. This was most pertinent in terms of time; *'how much can I achieve with the person within that time frame'* (Emma, SLT). Or *'I could provide AAC intervention but will I actually be able to follow through and source a device in time'* (Tracy, SLT). Lack of continuity between services was also flagged; would the management plan for the patient be carried out in the next setting? For example Julie (SLT) illustrates; *'the problem with the hospices is that there aren't speech therapists employed'* which is *'a big gap'* (Vicky, SLT).

3.4 Theme 2: Referral matters

This theme discusses the specific factors influencing referrals to SLT and the issues which impact on referral practices in the hospital setting. Figure 2 below illustrates theme 2 including organising and basic themes.

Figure 2: Theme 2: Referral matters



3.4.1 Specific factors

A prominent factor affecting referrals to SLT services was the patient’s diagnosis or prognosis. Specifically, SLTs said they were *'more relevant to certain teams'* (Catherine, SLT) with *'high levels of referrals from the stroke team, neurology, head and neck cancer and medicine for the elderly'* (Alison, SLT). The importance of early referral was a large point of discussion specifically to document patient’s wishes. *'Having their wishes and their directives documented in advance while they've still got the level of functioning'* is a vital piece of work says Emma (SLT). HCS also agreed with early referrals to SLT as best practice. Charlotte (HCS) says:

'When you're looking at end stage dementia-patients who have developed dysphagia-I think it's good to refer early so we can prevent complications like aspiration or pneumonia'.

It was agreed that with late referrals *'there is less to offer'* (Julie, SLT). Suzanne (HCS) also says *'if someone is very far advanced on their final journey there is no point in sending a referral'*.

3.4.2 Barriers to access

One barrier to accessing SLT services was the conflicting perceptions raised by the HCS on the role of the SLT in palliative care. Jane (HCS) says they *'wouldn't necessarily think of SLT first off'* and the team might *'just manage as best they could themselves'* (Anna, HCS). Interestingly, some HCS felt SLT were not seen as primarily involved in palliative care and *'SLT is not a useful resource at end of life'* (Jane, HCS). Kate (HCS) agrees *'I'd only see social work, nursing and doctors primarily involved in palliative care'*.

Strikingly, Suzanne (HCS) said *'I only considered the role of the SLT in palliative care when asked to do this study'*. Contrastively, other HCS felt SLT had a role from admittance to hospital to end of life and SLT services were *'probably underutilised'* (Mary, HCS) with Sarah (HCS) stating *'if it improves quality of life then there is a role for SLT in palliative care'*. Additionally, SLTs raised the issue of how their dysphagia role is perceived by other team members; *'I don't think they have that knowledge that we do more than modify'* (liquids- Emma, SLT). They also said the level of referrals received was dependent on an individual's knowledge. Zoe (SLT) explains:

'We might have someone who knows loads about what speech therapists do and have to offer so we get loads of referrals for that 6 months while that person is on rotation'.

Julie (SLT) agrees *'it's so different across the doctors', 'there's no consistency that we're constantly involved'*.

There was some disagreement on withdrawal of referrals during the focus group with some SLTs saying it *'happens a lot'* (Tracy, SLT) and others highlighting withdrawals are agreed together with the team if it's appropriate. SLTs also felt they could withdraw a referral if needed; *'okay I'm actually gonna call it myself and say there's nothing I can*

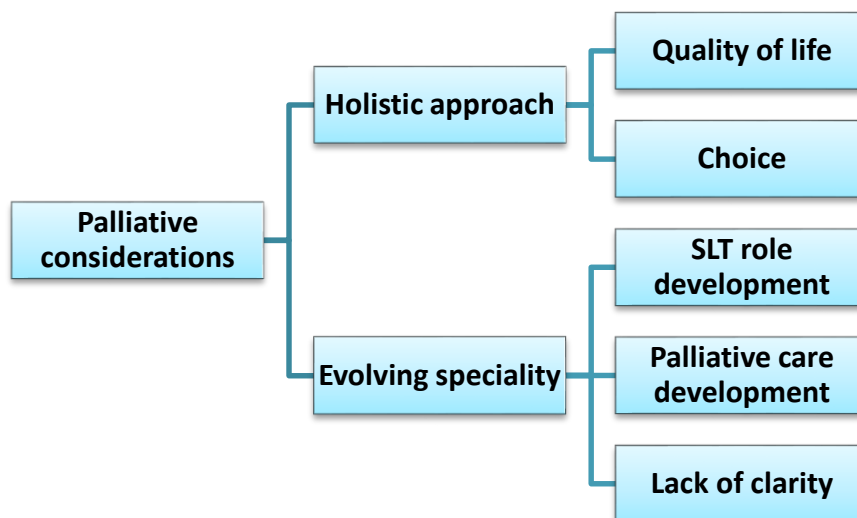
offer, it's not appropriate' (Catherine, SLT). General consensus was evident between the SLTs and HCS that referrals would not take place if the patient was actively dying; *'last few days, less is more'* (Charlotte, HCS). Similarly SLTs highlighted minimum intervention was warranted in the last few days and they take a *'step back when actively dying'* (Julie, SLT). Emma (SLT) emphasises a key issue for SLTs when referrals are withdrawn:

'This person is now for palliative care. So you're just told you don't need to go near them. I find myself in a strange position because you're trying to gauge what they mean, do they not know what I can offer or has this person just gone beyond needing me completely'.

3.5 Theme 3: Palliative considerations

This theme incorporates the development of palliative medicine and the importance of adopting a holistic approach to patient management. Figure 3 below illustrates theme 3 including organising and basic themes.

Figure 3: Theme 3: Palliative considerations



3.5.1 Holistic approach

Quality of life emerged as a central component to palliative care and was emphasised by all participants. Comfort was highlighted as pivotal to palliative care; *'it's much more based around the person being comfortable, making them happy, optimising their last time'* (Alison, SLT). Kate (HCS) agrees *'at end of life, comfort and patient quality of life is the key piece'*. SLTs were viewed as being central to providing this type of care with Mary (HCS) emphasising *'without SLT input, the quality of life and outcomes for patients would*

be very poor'. SLTs also highlighted that risk management of dysphagia symptoms was an important factor *'once the risks are acknowledged it's much more about the person being comfortable'* (Vicky, SLT).

The prioritisation of patient choice and family wishes were emphasised by all. Sarah (HCS) illustrates this; *'so a patient who is palliative can enjoy whatever he likes but in a safe kind of way'*. The role of the family is seen as key in palliative care; *'teams are speaking more with families and documenting families' wishes'* (Zoe, SLT). Emma (SLT) says common practice is *'ultimately handing over the responsibility or decision making to the family'*. Different patient attitudes to the dying process and SLT input emerged also:

'There's another attitude of that I'm at the end of my life and I've been told that there's nothing more that they can do for me so what's the point?' (Julie, SLT).

SLTs respected a patient's choice to decline SLT input. For example *'I have another patient who does not want to see me, you know...please leave me alone'* (Vicky, SLT).

3.5.2 Evolving speciality

A core element to palliative care working is that as a medical speciality it has developed and *'evolved over time'* (Tracy, SLT). Catherine (SLT) explains; *'palliative care has changed over the last ten years; previously palliative care was just end of life'*. Emma (SLT) adds *'the continuum is very broad'*. Catherine (SLT) also says, in the hospital *'the care of people who are palliative is highlighted more'*. HCS also emphasised the development of palliative care; *'palliative medicine is huge now, it's not just actively dying'* (Charlotte, HCS).

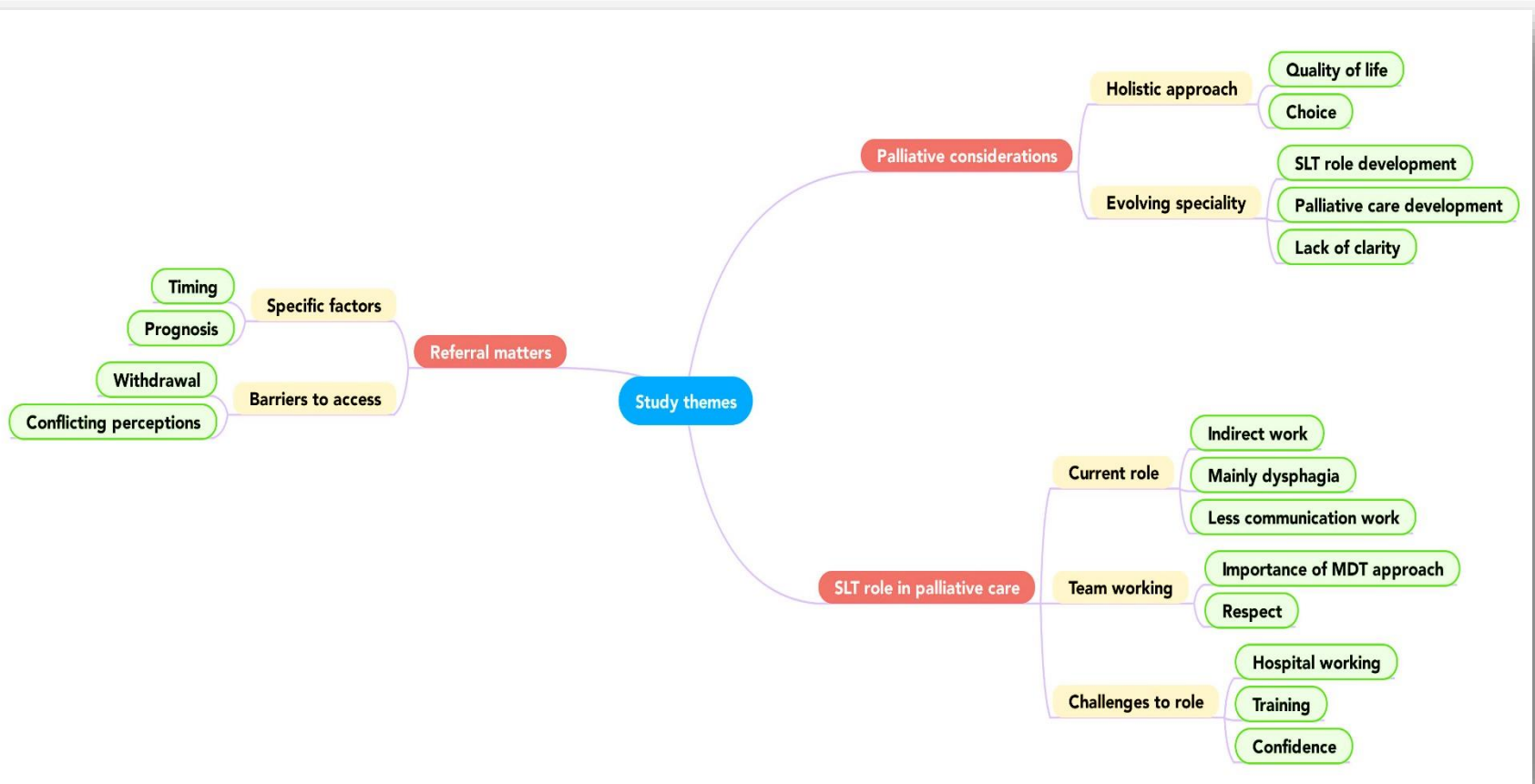
It was also highlighted that although the speciality has evolved there is a lack of clarity over what the exact meaning of palliative care is. Anna (HCS) says the idea of palliative measures is *'very nebulous'* and *'what do we mean by that?'*. Tracy said SLTs often ask *'how palliative'* is a patient. They also agreed that the changing conditions of patients effects palliative working:

'It's not an exact science so it's hard on medical teams and hard on us, people can be given months to live and pass away within a week' (Emma, SLT).

SLTs felt their role in palliative care has also developed; *'we feature more'* (Julie, SLT). Vicky (SLT) agrees *'we're certainly more involved, I would feel, than we have been 5 years ago'*. SLTs also highlighted AHPs *'have a much bigger role within the hospital now'* (Zoe, SLT). With this role expansion, SLTs also emphasised there is an *'increased awareness of the role of the speech and language therapist'* and the role *'will continue to develop'* (Catherine, SLT). However, further development of the role was strongly advocated. Alison (SLT) says *'I'm not sure as a profession we have actually thought about what we can actually offer to people'*. Tracy (SLT) agrees:

'We need to identify what that role is specifically as a group of therapists and as a professional standard first'.

Figure 4: Mind map of the study's themes



4. Discussion

This study explored the perceptions of the SLT role in palliative care. There are multiple factors influencing the role particularly the HCS' opinions of what SLTs have to offer and the confidence levels of the SLTs themselves. The findings reveal that palliative care is a complex area to work in for SLTs and a number of key points are worthy of discussion. The themes SLT role in palliative care, Referral matters and Palliative considerations will be considered under the following headings.

4.1 Scope of practice

The development of the SLT role in palliative care has led to increased role awareness and inclusion in multidisciplinary teams. In this study, dysphagia was highlighted as a main role with the majority of referrals to SLT being dysphagia based. This is similar to what Groher and Groher (2012) found. Diet modification, risk management, comfort measures and maintaining a functional swallow were all components of dysphagia input in this study. Indeed Pollens (2004) outlines comfort measures and minimising risk as crucial aspects for dysphagia management. Difficult decisions in terms of balancing the burden versus the benefit of eating were central to the SLT role in dysphagia. This equates to weighing a patient's quality of life i.e. the pleasure derived from eating versus the aspiration risk.

Communication is also an important element in maintaining quality of life (Salt *et al* 1999) and this was emphasised in this study. SLTs felt they could offer palliative patients supportive communication strategies including visual aids and AAC. However, it emerged there are obstacles to implementing communication work, with some HCS unsure of what SLTs can offer in this area. This lack of awareness could have a knock on affect for patients accessing SLT services for communication input. This is a concerning finding given that communication difficulties can impact on a patient's emotional well-being (Pollens 2004). Additionally, Radtke *et al* (2011) found that core members of the palliative care team (doctors and nurses) are often not trained in the use of communication strategies. If HCS are not adequately equipped to facilitate communication with palliative patients and SLT services are not utilised, then how will this affect patients who have communication difficulties at end of life?

4.2 The pivotal patient

The prioritisation of patient choice along with the family's input was a primary finding in this study. Optimising quality of life was pivotal in providing good palliative care. This finding is supported by Pollens (2012) who affirms quality of life means a patient is able to communicate their wishes, needs and feelings. Similarly, the importance of early referral to SLT was highlighted as paramount in order to document the patient's wishes for their care. This allows patients to make informed decisions around pertinent end of life decisions, express choice and retain a sense of control over their own lives (Salt *et al* 1999). On the other hand, SLTs also respected a patient's choice to decline SLT input and to be left alone in their final days. Indeed, Toner and Shadden (2012) highlight that SLTs must be sensitive to different patient perspectives on dying.

Working with families to support them through the palliative process was important for the SLT role. SLTs can offer expert advice to families around end of life swallowing and communication difficulties. Toner and Shadden (2012) emphasise that helping families to understand the changes that take place during the dying process may reduce their concerns. Working indirectly with families and building relationships with them is an important aspect of the SLTs role as it offers a support system to help families cope (WHO 2002).

4.3 Team working; optimum or flawed?

Adopting a multidisciplinary team approach was emphasised by all participants as a key piece for optimal palliative care working. This finding reflects best practice guidelines in Ireland (IHF and HSE 2008). SLTs are also highly respected and are valued members of the team in the hospital. Working with the team frequently involves the SLT providing consultations and giving advice on specific cases. This finding supports Pollens' (2004) proposal that indirect working is one of the roles for SLTs in palliative care.

However, several barriers to effective team working were also evident in this study. Specifically, it emerged that some HCS have a lack of knowledge of the role of the SLT in palliative care. Of particular note is that SLTs are not seen as a useful resource at end of life and they are not seen as primarily involved in palliative care. Perhaps managing other symptoms, such as pain, are prioritised over dysphagia or communication needs. It is

worth considering the implication of this finding for patients accessing SLT services as found by Thomson *et al* (2006). After all, the imbalance of HCS utilising SLT services may result in patients falling through the cracks and not receiving the care they need at end of life.

Similarly, the withdrawal of referrals raised a conundrum for SLTs; do the team know what SLTs can offer to palliative patients nearing the end of their life? Furthermore, all HCS reported they received no training about the SLT role during their qualification and only came across SLTs on the job in the hospital. This finding may also be interpreted as a barrier to an effective multidisciplinary approach as team members may not be aware of the benefits SLTs can offer their patients. O'Reilly and Walshe (2015) outline training for team members about the SLT role in palliative care is an important step to overcome these issues and facilitate collaborative working.

4.4 Issues specific to palliative care working

Varying prognoses for palliative care patients and rapidly changing conditions was a factor affecting SLTs role. This was particularly evident in terms of the timing and appropriateness of referrals. It was agreed that referrals would not be appropriate if the patient was actively dying and minimum intervention was warranted in that case.

Working in a hospital setting also adds to the complexity of working in palliative care for SLTs especially in terms of time. SLTs have large caseloads and the nature of their work in hospitals can limit the types of interventions they can implement, e.g. complex AAC interventions.

The understanding of the SLT role in palliative care also extends beyond the hospital. A significant finding was the difficulty in continuing the patient's management to hospice settings due to the lack of SLTs employed there. Frost (2001) outlines the role of AHP's in hospices has not been addressed sufficiently in the literature. Furthermore, there is a need for clarifying the scope of practice of AHP's in hospices as they play a vital role in the final stages of a palliative patient's life (Frost 2001). This finding is particularly relevant as currently there are no SLTs employed in hospices in Ireland which is a barrier to providing holistic palliative care to patients who transfer from hospital to hospice settings.

Another key finding was the lack of training for SLTs working in palliative care both at undergraduate or postgraduate level. The IHF (2006) reports there are no specific references to palliative care within course curriculums in undergraduate or post graduate SLT programmes in Ireland. Additionally, Rivers *et al* (2009), Mathisen *et al* (2006) and Roe (2004) outline palliative care education has not been provided in SLT training programmes. The Department of Health and Children (2001) recommend that SLTs should have a level of palliative care competency relevant to the requirements of their post. Furthermore, the IHF (2006) outline that SLTs working in hospitals with palliative populations may have considerable educational needs in the area of palliative care.

SLTs' confidence in their management decisions was affected by feelings of fear, intrusiveness and uncertainty of what they can offer to patients. Similar findings were reported by O'Reilly and Walshe (2015) who found that SLTs working in palliative care were unsure whether their contributions were adding to the patient's quality of life or not. It is worth considering how a lack of confidence may affect SLTs clinical working. Particularly as Bandura (1977) states individuals who lack self-confidence are less likely to succeed in achieving a goal than individuals who have high levels of confidence.

4.5 Developments

This study highlighted the development of palliative medicine as a speciality where end of life care now incorporates a wider spectrum of patients (Department of Health 2008). This expansion has led to a reported increased role for SLTs which is supported by Sharp *et al* 2006. Despite this, palliative care as a speciality is nebulous in its origin with the fast changing conditions of patients affecting management decisions. Critically, SLTs emphasised that in order to provide the best patient care further role development and clarification of what can be offered is of paramount importance. This finding is supported by O'Reilly and Walshe (2015) who also advocate strongly for the development of practice guidelines for SLTs working in palliative care.

4.6 Limitations

Although this study has many strengths, it is not without its limitations. Firstly, it would have been beneficial to interview more doctors than the present study did. As doctors tend to be the primary referral sources in hospital settings this would provide for a more

comprehensive view of the perception of the SLT role from a medical perspective. Secondly, on reflection, some of the questions used for the individual interviews were too broad. In considering that some of the responses from HCS were quite general, more probing on specifically what SLTs can offer to palliative patients in terms of dysphagia and communication would have been valuable.

4.7 Conclusion

This study identified that although SLTs are perceived to have a role in palliative care, uncertainty still exists regarding this role. SLTs' lack of confidence along with a lack of training or professional guidelines hinders clinical working in palliative care. Additionally, conflicting perceptions by HCS on the role of the SLT affects the referral process and ultimately patients accessing SLT services. In considering the aforementioned issues and in the context of increasing concentration on palliative care services in Ireland, there is a need for increased development and awareness of the SLT role in palliative care in order to provide holistic care to patients.

4.8 Recommendations

The results of this study provide a basis for further research. Firstly, SLTs working in hospitals have considerable education needs (IHF 2006) which are not currently accounted for in SLT undergraduate or postgraduate programmes. This is an area which warrants investigation. Perhaps future research could examine how Irish SLT education providers are covering palliative care working in their programmes. Secondly, future research could explore the perception of the SLT role from the perspective of patients. Kennett and Payne (2010) found that good professional relationships fostering a communication style of openness and availability was preferred by palliative patients. Gathering patients' opinions is critical given that they are the recipients of palliative care services (Morss *et al* 2015).

This study highlighted a need for professional guidelines for SLTs working in palliative care. If SLTs are to work according to best practice guidelines proposed by the IHF and HSE (2008), then the profession itself, namely the IASLT, needs to set professional guidelines and standards for SLTs working in palliative care. It is also recommended that role development in palliative care be prioritised through specific training courses for

SLTs. In addition, given that SLTs work with people who have life limiting conditions, palliative care needs to be addressed at an undergraduate level for SLTs. The introduction of training and education measures would increase professional confidence for SLTs working in palliative care.

In terms of team perceptions, contrasting perspectives of the SLT role in palliative care were evident from this study. In order to increase awareness of what SLTs can provide it is recommended for interdisciplinary professional discussion to take place between teams regularly. Strategies to educate clinical team members may result in improved access to SLT services for patients (Pollens 2012). In particular, advocating for the importance of communication at end of life would contribute significantly to patients' quality of life (Salt *et al* 1999).

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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 on the role of 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?

- [REDACTED] Hospital doctors, nurses, medical social workers and dieticians who work with patients receiving palliative or end of life care.
- [REDACTED] 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 [REDACTED] 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 [REDACTED] 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?

- [REDACTED] 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.
- [REDACTED] hospital SLTs will be asked to participate in a once-off focus group (of 8 [REDACTED] Hospital SLTs) lasting 30-45 minutes which will be facilitated by the Research Assistants.
- Exact locations in [REDACTED] Hospital will be agreed and confirmed with participants nearer to the time.
- This study is specific to [REDACTED] 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 [REDACTED] Hospital and the University of Limerick. Dr Arlene McCurtin Course Director for the SLT programme is the University of Limerick co-ordinator. [REDACTED] Clinical Specialist SLT/Practice Tutor and [REDACTED], Senior Speech & Language Therapist/Practice Tutor are [REDACTED] 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, [REDACTED], SLT Manager [REDACTED] 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?

- [REDACTED] 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 [REDACTED] 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, [REDACTED], SLT Manager at [REDACTED] or on [REDACTED].

Appendix B: 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 C: Questions and probes

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?
 - a) For SLTs in general?
 - b) For SLTs in the hospital?
- ii. How do you see it changing in the future?
 - a) For SLTs in general?
 - b) For SLTs in the hospital?

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?

Semi-structured interview 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 D: Example of thematic analysis process

Theme: Palliative considerations, holistic approach

Nodes	Codes	Basic themes	Organising theme	Main theme
Not comfortable Good quality, comfort-centred care Pain really important Symptom management Person comfortable Comfort measures Comfort is key piece Concerns for discomfort Solely focus on comfort Comfort more preferable to treatment Comfort levels Prioritise comfort levels	Comfort	Quality of life	Holistic approach	Palliative considerations
Significant distress Severe pneumonia Enjoy food safely Eating and feeding done safely Role for SLT in comfort re swallowing? Coughing and choking on regular fluids Weighing quality of life vs risk Balance burden vs benefit for feeding	Safe feeding: balancing act	Quality of life	Holistic approach	Palliative considerations
Prioritise quality of life Improve quality of life Patient-devastated Patient-centred care Wanted to say so much Making them happy Optimising their last time Family prioritising their last time Person can say their wishes for end of life care	Patient-centred	Quality of life	Holistic approach	Palliative considerations

<p>Quality of life is key piece End of life- people need quiet End of life- need time to get used to it How is comfort perceived? Dysphagia and communication not seen as symptoms Dysphagia and communication not seen as having impact on pain Comfort isn't always unrestricted diet and fluids</p>				
<p>Documenting family wishes Family wish comfort to be priority Family meeting Family discussion Handing-over decision making to family Family-SLT input may not be appropriate Family choose diet</p>	Family wishes	Choice	Holistic approach	Palliative considerations
<p>Family time Don't want to be interrupted It's all about the family No interruptions-by lots of different people</p>	Family time prioritised	Choice	Holistic approach	Palliative considerations
<p>Patient-“Please leave me alone” End of life- “What’s the point?” Different patient attitudes Valid emotion Prioritising patient’s wishes Patient may decide- no SLT Patient wants hospice</p>	Patient’s choice	Choice	Holistic approach	Palliative considerations
<p>Tapered to each individual Basing decisions case by case Every case is individual Every case needs to be discussed Prioritise patient’s wishes</p>	Individualised care	Choice	Holistic approach	Palliative considerations

Theme: Palliative considerations, evolving speciality

Nodes	Codes	Basic Theme	Organising Theme	Global Theme
<p>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 Palliative care means different things to different people Palliative care-very nebulous</p>	Unclear terminology	Lack of clarity	Evolving Speciality	Palliative Considerations
<p>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</p>	PC is not an exact science	Lack of clarity	Evolving Speciality	Palliative Considerations
<p>Much bigger role Not just end stages SLTs feature more More of an appearance</p>	Increased role	SLT role development	Evolving Speciality	Palliative Considerations

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	Increased awareness	SLT role development	Evolving Speciality	Palliative Considerations
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 increase role in education	SLT role development	Evolving Speciality	Palliative Considerations
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	Future developments	SLT role development	Evolving Speciality	Palliative Considerations
SLT role has developed with PC development	Adapting role to PC development	SLT role development	Evolving Speciality	Palliative Considerations

Whole package given to PC patients Adapting role to PC development				
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	Evolved in recent years	PC development	Evolving Speciality	Palliative Considerations
Still emerging Still discovering PC What it really means to be palliative Medicine evolving Things are shifting Things are moving Palliative medicine huge now	Still emerging	PC development	Evolving Speciality	Palliative Considerations

Appendix E: Focus group summary sheet

Date: 26th January 2015

Facilitators: Jemma Colclough, Ciara Gleeson and Rebecca Burke

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

Trends/Topics	Summary of discussion
1. Role development	<ul style="list-style-type: none"> ➤ 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	<ul style="list-style-type: none"> ➤ 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	<ul style="list-style-type: none"> ➤ 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	<ul style="list-style-type: none"> ➤ 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 palliative care team
5. Confidence in role in palliative care	<ul style="list-style-type: none"> ➤ 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 clarity and confidence as a profession in palliative care ➤ Insufficient training for SLTs for discussing issues concerning death with patients