Communication disorders in palliative care: Investigating the views, attitudes and beliefs of speech and language therapists

Rosy Hawksley, Fiona Ludlow, Heather Buttimer & Steven Bloch

Steven Bloch, Senior Lecturer, Department of Language and Cognition, University College London, London UK

Rosy Hawksley, Speech and Language Therapist, Children's Integrated Speech and Language Therapy Service for Hackney and the City, London UK

Fiona Ludlow, Speech and Language Therapist, Sutton Education Services Ltd., London UK

Heather Buttimer, Speech and Language Therapist, Chelsea Children's Therapy, London, UK

Correspondence:

Rosy Hawksley
07713185822
rosy.hawksley@gmail.com
Work address: Children's Speech and Language Therapy, **Room 31, D Block, St Leonard's Hospital, Nuttall Street, London, N1 5LZ**

Abstract

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Speech and language therapists (SLTs) provide intervention for communication and swallowing to patients with life-limiting conditions such as dementia and head and neck cancer. The role of the SLT in palliative care is difficult to define. Much is known about the clinical aspects, however little is known about the core values, beliefs and expectations of SLTs working in this sector, particularly with regard to their role in supporting patients' communication. Through a series of semi-structured interviews and a follow-up focus group, this report aims to form a picture of the current experiences and views of SLTs about their communication role in palliative care. Results suggest that SLTs are forging a self-identity in a sector that is itself constantly evolving, which causes difficulties in defining their role. Participants report that other health professionals have a poor understanding of the SLT's role. SLTs may benefit from palliative care-specific guidelines and increased inter-professional awareness of their role to become better integrated into the palliative care sector.

Introduction

Speech and language therapists (SLTs) assess and treat children and adults with disorders of speech, language, communication or swallowing. In adults, such difficulties may be caused by age-related or acquired conditions including head & neck cancer, Parkinson's disease, stroke, or dementia. SLTs work alongside patients' families, and the wider multi-disciplinary team (MDT), to identify communication difficulties and provide appropriate support to facilitate effective communication. This is important in terms of facilitating and advocating patient choice, a core principle of the NHS agenda around patient care and palliative care (Darzi, 2008; Department of Health (DH), 2008; 2015).

In recent decades, SLTs have expanded their role to include work with palliative patients, working in a broader range of settings including hospitals, nursing homes, hospices, and in the community (Eckman & Roe, 2005; Pollens, 2012). Increased recognition of the importance of specialist MDT input has helped to raise the profile of the SLT in palliative care (Eckman & Roe, 2005). However SLTs' membership within palliative care MDTs can be inconsistent between clinical settings, risking their marginalisation and belated patient input (AHP Palliative Care Project Team, 2004).

Current literature summarises the role of the SLT in palliative care as follows (Salt, Davies & Wilkinson, 1999; Pollens, 2004; Eckman & Roe, 2005; MacDonald & Armstrong, 2010):

i) assessment and intervention for feeding and swallowing

ii) facilitating communication between patient, family, healthcare professionals, others e.g. lawyers

iii) communication assessment and implementing strategies to support decision-making, independence, quality of life

iv) empowering patients and families to make informed choices about their future through facilitation of effective communication (NCPC et al., 2011; NHS, 2010)

v) assessment and input towards cognitive capacity

vi) counselling and helping parties plan for changes in feeding, swallowing, speech, cognition

vii) informing MDT about swallowing, communication, cognition

viii) facilitation of ethical decision-making regarding feeding and swallowing

ix) provision of alternative and augmentative communication (AAC)

The literature clearly recognises a role for SLTs in palliative care; elevating a patient's quality of life (Schleinich, Warren, Nekolaichuk, Kaasa, & Watanabe, 2008), and ameliorating communication and swallowing difficulties even in the late stages of illness (Chahda, Mathison & Carey, 2016).

With the concept of 'palliative rehabilitation' gaining greater traction in palliative medicine, palliative teams more frequently focus on restoration of former function and patient independence, rather than only symptom management (Kane Miller & Willging, 2012). The literature recognises that specialist communication input from SLTs may be required throughout the palliative journey from diagnosis and as a patient's health fluctuates, not just in the final stage of life (Pollens, 2012).

However, a lack of suitable guidance on their work in this sector prevents SLTs from fully securing and defining their role (Schleinich et al, 2008). Additionally, the perception persists that SLTs can effect only limited change in the late stages of terminal illnesses (Pollens & Lynn, 2011).

Available evidence regarding the role of the SLT in palliative care is based largely on literature reviews, surveys and professional overviews. Few studies are methodologically generalisable to other palliative settings. Most look at the practical tasks involved in the role: few look at the attitudes and beliefs underlying SLTs' practice within the palliative care sector. Previous research concluded that the SLT's role in this field is 'under-resourced, under-acknowledged, and poorly developed' (O'Reilly & Walshe, 2015, p.1), highlighting the need for additional research to further

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define the role and support other healthcare professionals to identify when and how SLT input is required (Eckman & Roe, 2005).

Collis & Bloch's (2012) research into assessment and treatment practices by SLTs working with patients with progressive diseases identified a discrepancy between SLTs' ideals and values, and the clinical reality, which was found to be much more impairment-focused than SLTs desired. The authors queried whether the role of the SLT in palliative care were not much broader than the literature suggests; shaped by a range of factors including SLTs' attitudes and beliefs and the patients and professionals around them. A knowledge of the clinical tasks involved in this emerging role may not be enough: SLTs must engage in self-reflection and identify how clinicians' views, attitudes and beliefs affect the types of services provided and shape the way they operate in this new field. These insights could support the development of appropriate guidance for SLTs in palliative care.

2. METHODOLOGY

Following University Research Ethics Committee approval SLTs with a range of clinical experiences in palliative care were invited to participate in the study. Twelve SLTs elected to participate. This group was self-selected via a palliative care Clinical Excellence Network event. No participant worked exclusively with palliative care patients however all participants did encounter this client group in their role to a greater or lesser extent. All participants were female working within NHS band 6 and 7 posts – apart from one private sector SLT - in Greater London and the South-East UK. Participants' SLT and palliative experience varied, from four to 13 and one to 13 years respectively. Participants had an average of 8.25 years experience as an SLT, and 6 years within palliative care. Collectively posts spanned acute, rehabilitation and community settings, involving head and neck

cancer and progressive neurological caseloads. No SLTs working exclusive in a hospice setting were identified during recruitment.

The initial phase of the study featured the development of a pilot semi-structured interview schedule. This was informed by the existing literature and a specialist SLT in palliative care. It was then trialled with two of the palliative SLTs. Their responses allowed further refinement of the interview schedule. Semi-structured interviews were then conducted with 10 participants at their place of work or preferred setting, to discuss their experiences of and motivations for working in this sector. All interviews were audio-recorded, each lasting between 55-90 minutes, and were then orthographically transcribed.

The data were analysed using inductive thematic analysis (Braun and Clarke, 2006). This allowed latent themes to be identified and organised in a bottom-up approach without the researchers being influenced by preconceived ideas or hypotheses, according to a six-phase thematic analysis process: i) Familiarisation with the data; ii) Generating initial codes; iii) Searching for themes; iv) Reviewing themes; v) Defining and naming themes; vi) Producing the report. All four authors were involved in the coding, reviewing and naming process to achieve consensus.

In a second phase of the study, the original interview participants were invited to participate in a focus group to discuss the themes drawn from the interviews. This approach contributed to the accomplishment of data saturation, that is, the point at which additional data did not lead to any new emergent themes. Five participants self-selected to attend a focus group. The small group size provided a secure environment conducive to discussion, whilst the participants' varying settings of work and years' experience provided some heterogeneity and allowed exploration of different perspectives and opposing views within the same group (Kitzinger 1994). Random sampling was not possible in this study due to a limited number of available participants. The five focus group

participants were judged to representative of the wider interview group with a comparable spread of adult clinical and palliative experience. It was also noted that the five focus group members worked in a representative range of settings: acute, out-patient and community/domiciliary.

Two members of the research team acted as moderators, guiding the discussion using a loosely structured schedule, polarity statements and anonymous quotations from the initial interviews in order to elicit in-depth exploration of the existing themes as well as any unanticipated topics. The data from the focus group were subsequently analysed using inductive thematic analysis (Braun & Clarke, 2006), and triangulated against the individual interview data to confirm the presence of correlating themes within the two data sets. Triangulation of the data minimised researcher bias, further supporting the inductive process.

Results

Analysis of the individual interviews generated four themes: *conflict*, *pioneering*, *justifying the role*, and *dealing with death*. Comparison of the data sets revealed significant overlap between the issues discussed in the interviews and focus group. These issues were synthesized into an overarching theme, *conflict*, and three subthemes – *pioneering*, *legitimising the role*, and *dealing with loss*, presented below as a final thematic model (Fig.1):

Fig.1. New model of themes and subthemes
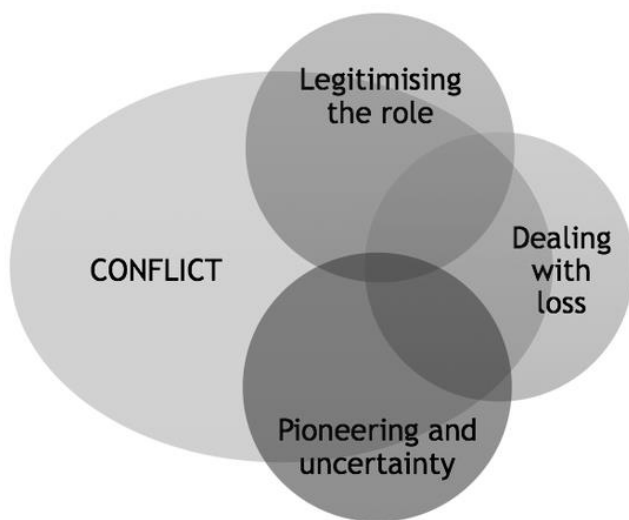
Overarching theme: 'Conflict'

Summary:

- SLTs work towards a 'good death' for patients

- SLTs feel increased responsibility towards palliative patients

- Poor interprofessional understanding of SLTs' role leads to a lack of referrals

- Dysphagia role prioritised over communication

The 'good death'

The data revealed SLTs to be creating a professional identity for themselves in the face of various conflicts and barriers. SLTs work towards the core values of quality of life, comfort, and closure in order to achieve a 'good death' for their patients: these mirror the World Health Organisation's (2002) definition of palliative care.

S1: I always think about them *[patients who have died]*, and the pathway I've had with them and whether I've felt satisfied with that pathway.

Despite their efforts, SLTs often feel that this 'good death' was not achieved, due to factors such as insufficient clinical time with the patient, or late referrals. This can be emotionally challenging and produce conflicting feelings of guilt and uncertainty about the effectiveness of their work:

S4: You've spent the last eighteen months going 'when she goes, this is going to be awful', and I was like no, actually, because it was right for her at - I think I'm more emotive when I feel that there's been some frustrations.
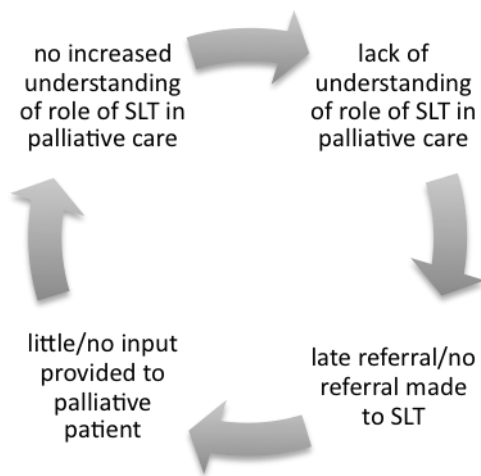
Workplace conflict

Discussions revealed inter- and intra-professional conflicts. SLTs often receive late referrals from other professionals, often when the patient's difficulties are too severe to achieve meaningful change:

P10: It's the constant battle … in the hospitals … to make people realise that you [SLTs] can help … and … that's doubly true for palliative care patients.

Interviewees repeatedly raised their role in supporting eating, drinking and swallowing difficulties (dysphagia) in interviews. While this report focused on communication, the dysphagia role emerged as an area of conflict in the workplace, as participants felt that their expertise in supporting communication was often considered as an afterthought, or forgotten altogether, with most referrals being for dysphagia.
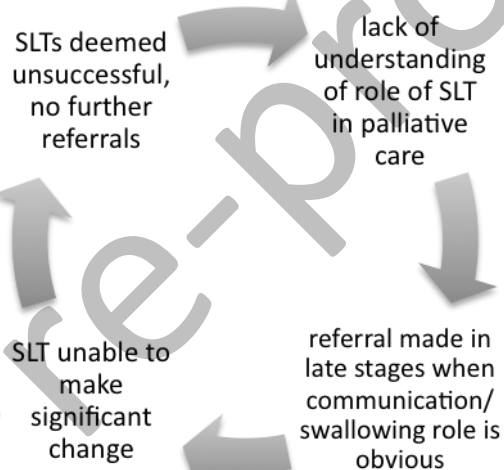
Many participants felt that SLTs could make a greater impact if the MDT and patients were to develop skills in recognising when referrals for SLT, particularly for communication support, are required. This lack of referrals can be represented as a self-perpetuating cycle (Fig.2):

Fig. 2. Poor understanding of SLT communication role in palliative care

no increased understanding of role of SLT in palliative care → lack of understanding of role of SLT in palliative care → late referral/no referral made to SLT → little/no input provided to palliative patient →

which also casts doubt on the validity of the SLT's role in the palliative care (Fig.3):

Fig.3. Poor perception of SLT's validity in palliative care

SLTs deemed unsuccessful, no further referrals → lack of understanding of role of SLT in palliative care → referral made in late stages when communication/ swallowing role is obvious → SLT unable to make significant change →

Interpretations of 'palliative'

Participants generally defined 'palliative care' as beginning early in the palliative journey, even from the patient's' diagnosis. In contrast, for some professionals, palliative care may refer to the last few days of life. This results in a reduced level of input from SLTs:

S3: I've even had doctors going 'but they're not dying now', and I'm like no but they are on a palliative journey…they're still palliative, they're not going to recover from this.

Participants felt that perceptions of palliative care and the recognition of the SLT's potential role were inherently linked:

P10: The benefit of having more speech therapy more widely accepted as part of palliative care would probably be by default palliative care being more accepted full stop.

Emotional conflict

SLTs, like other healthcare professionals, are vulnerable to the effects of workplace conflict. These conflicts are intensified, however, when working with palliative patients: much lies at stake, and with limited professional guidance, responsibility towards patients is felt more acutely. This can result in burnout, guilt, and a lack of interprofessional trust.

Subtheme 1: Pioneering and uncertainty

Summary:

- SLTs evolve their practice to address limitations of traditional SLT approaches

- Palliative patients require a different management approach and skillset

- Traditional methods of SLT do not contain appropriate outcome measures

- SLTs feel they have a role within palliative care, but that this is not always recognised

SLTs as pioneers

SLTs working in palliative care act as 'pioneers', simultaneously forging a role for themselves in a burgeoning area of SLT, and attempting to conform to the guidelines of traditional SLT. The

'pioneer' role appears to have evolved out of necessity, due to the unique nature of palliative

patients:

> S3: There was a realisation quite early on that actually these patients were very different, they
>
> weren't the type that you could go in and say 'oh dear, you can't swallow, let's do this this and
>
> this'….and walk off forty-five minutes later.

The role extends beyond the traditional boundaries of SLT:

> P5: In palliative care, a lot of what you do goes well beyond the bounds of what traditional speech
>
> and language therapy is … you can end up playing a role that you question.

'Traditional' SLT lacks appropriate assessments, outcome measures, and guidelines to cater to these

unique demands, and have limited methods of measuring the value of their input, as traditional

outcome measures are unsuited to palliative patients:

> S2: you can't necessarily give a patient-reported outcome measure to any of the families, it's picking
>
> the timing, you know, the wrong moment could end your therapeutic relationship, and it's not worth
>
> it for a positive feedback form to do that to a family.

In response, SLTs are developing palliative care-specific interventions and outcome measures:

> S5: We've been looking at doing more patient stories…it's an interview with the patient of their
>
> journey, and it's kind of focusing on how the healthcare aspects have been for them.

SLTs expressed satisfaction at the freedom they enjoy in evolving the service and bending the boundaries of their role. This satisfaction, however, lies at odds with the uncertainty they face from the lack of feedback about their role and expectations to follow Evidenced Based Practice when there is no gold standard.

Subtheme 2: Legitimising the role

Summary:
- The role of the SLT in palliative care is poorly defined
- Guidelines available to SLTs in palliative care are unsuitable, as are targets set by managers
- SLTs request palliative care-specific guidelines and best practice to justify their contribution to palliative care

A role for SLTs in palliative care

SLTs firmly believe that they have a legitimate role in providing care to patients with life-limiting conditions. However, the data confirmed their role to be poorly defined. Perceptions of the SLT's remit vary widely. SLTs often battle with other professionals to justify their value and provide input:

S4: I had a conversation with the therapist in the acute ward that was like, 'no I'm not sending him over to you.' 'Why?' 'We don't need you it's nil by mouth, his communication's fine.' 'Well, it's not going to be is it.' 'Well he'll call you then.'

Guidelines and their interpretation

Participants were unable to identify any clear guidelines for their work in palliative care. In the absence of palliative care-specific guidelines (excepting NICE cancer care guidelines), SLTs instead use an assortment of guidelines, e.g. NICE guidelines for Parkinson's disease, MND, nutrition and

saliva management. There is no consensus on *which* guidelines SLTs should refer to, as 'they're very rudimentary' (S3) and 'they're not all in one place and they're quite broad' (S2).

Pressure from above

Available guidelines are largely unsuitable for the palliative workplace. SLTs feel pressure – often from managers - to meet targets that are 'totally unrealistic to the workplace' (S1):

> S1: They're just a rod to hit us with, these guidelines sometimes.

SLTs request palliative care-specific SLT guidelines in order to better meet targets and increase their confidence working in this sector. However, SLTs face a conflict: a lack of guidelines allows them more flexibility in their role, yet without guidelines, SLTs experience difficulty in defining their role and justifying their place in palliative care.

Subtheme 3: Dealing with loss

Summary:
- SLTs experience loss throughout the palliative journey
- More intimate patient-therapist relationships are both necessary and unavoidable
- SLTs are more likely to breach their role boundaries

The burden of loss

All professionals working in palliative care must deal with the emotional demands of working with palliative patients and their significant others. However, discussions revealed that the burden of loss extends far beyond losing a patient. Loss is a constant presence along the palliative care pathway: SLTs experience loss of certainty about their role; loss of confidence in their own skills;

loss of optimism; loss of professionalism when faced with more intimate patient-therapist

relationships, and, crucially, a loss of control over the progress they can expect patients to achieve.

<u>Patient-therapist relationships</u>

The certainty that a patient will die adds a heightened sense of responsibility to SLTs working with

palliative patients, resulting in more personal, honest and intimate patient-therapist relationships.

SLTs strive to balance honesty with collusion, in order to preserve both the patient's hope and their

sense of realism:

> S5: *[Re. collusion:]* I struggle with this question so much, because I obviously don't think you should
>
> take people's hope away, but I also think we have a role in helping people with adjustment, and so I
>
> think if we're not completely working with people at some level to balance their hopes with some
>
> reality I think we're doing them a disservice when they get to end of life and they haven't been-
>
> aren't ready for it really.

SLTs describe themselves as being 'different' therapists when working with palliative clients, in their

personality and professionalism;

> S3: In a really odd way, I think I am more myself, I actually let a bit more of my own personality come
>
> out with people who are at that stage.

willingness to breach their role boundaries:

> S1: You will do things that are completely unrelated more for a person in an end of life situation than
>
> you would in acute. So if somebody said to you, 'oh my toe is really sore, could you have a look at it?'
>
> then you go in there and you look at the toe!

and intimacy of patient-therapist relationships:

> S4: Actually the husband was very touchy feely, very kissy kissy, all that kind of stuff, not in an, I want to say not an inappropriate way, but actually I remember thinking this would be inappropriate in any other situation...

SLTs defended this increased intimacy as careful and appropriate clinical decision-making. Earlier contact with palliative patients allows SLTs to become personally acquainted with patients, so that 'you're building that rapport, and gaining their trust so that they can talk about what the real issues are' (S3).

Discussion

This study has presented an investigation into the views, beliefs and experiences of SLTs working in palliative care. There has been a specific focus on their role in communication disorders.

<u>Conflict</u>

For SLTs to integrate themselves fully into the palliative workplace, it is important that the MDT has an informed understanding of their potential input and when referrals are appropriate. In fact, the limitations faced by SLTs in palliative care (e.g. lack of referrals, time, resources, training) are common to many professions working in palliative medicine. For example, the NCPC (2015) and Public Health England (2015) acknowledge a generalised lack of palliative training and inconsistencies in understanding of what palliative care entails, which may contribute to the lack of inter-professional understanding of the SLT's role in palliative care.

<u>Pioneering</u>

Our findings indicate that the SLT's role in palliative care eludes precise definition, due to its inherent flexibility. This inevitably leads to difficulties around measuring the value of SLT input and justifying their role. The need for SLTs to justify their communication management role to other healthcare professionals could be considered representative of a healthcare system in which perceptions of palliative care vary across professionals and services. As the average lifespan increases, the palliative care sector is experiencing rapid changes in its patient type and service model (Toner & Shadden, 2012; O'Reilly & Walshe, 2015). In addition, misconceptions of when palliative care begins can lead to gaps between patients' needs and their actual access to palliative services - indeed, within the UK National Health Service (NHS), the demand for palliative care far outstrips the supply (Waldron et al., 2011). Interpretations of palliative care may need to broaden so that SLTs may firmly find a place for themselves within its field.

The concept of rehabilitation in hospice and palliative care is growing in status (Roe & Leslie, 2010; Kane Miller & Willging, 2012), meaning that patients with terminal conditions increasingly work towards goals of independence and restoring communicative abilities, rather than simply limiting the progression of a condition. As this approach gains traction, the role of SLTs in palliative care for communication in particular may become more prominent as patients and the wider MDT seek to not only maintain, but also restore skills. Additionally with NHS reform advocating patient communication and choice (DH 2008; 2015), SLTs have a legitimate and pivotal role to empower palliative patients with communication difficulties to participate in their care and decision-making.

Legitimising

In this study SLTs are confident about when their input is necessary, however the flexibility and breadth of their work causes difficulties in creating a single clear set of guidelines to inform their work (Chahda et al, 2016). One possible option is for structured, profession-specific guidelines to

secure their place within the palliative care MDT, and ultimately reduce the uncertainty they feel working in a broad, flexible and indefinable role in an evolving healthcare sector.

Any guidelines created should be deliberately broad, to account for the flexible nature of SLTs' role, as well as the heterogeneous presentation of patients with life-limiting conditions. Communication disorders, in particular, can vary significantly in terms of severity and impact. Guidelines for SLTs working with adults with learning disability (ALD) take a more generalised approach to their goals and outcomes, working towards broad aims of quality of life, wellbeing, independence, choice, inclusion and civil rights (RCSLT, 2003; 2009): guidelines developed for SLTs working in palliative care may do well to follow this flexible model.

Dealing with loss

Given the high emotional demands of such work, and the drastic consequences of mismanagement, it is unsurprising that SLTs and other professionals are more open and personable with their patients, perhaps to compensate for feelings of powerlessness around patient outcomes. In light of this, it is important that palliative care staff receive sufficient support and bespoke training to support them with these difficult emotional aspects of their role, as well as training in dealing with death and dying for students prior to starting clinical work (Rivers, Perkins & Carson, 2009).

SLTs, and other professionals working in palliative care, are required to be comfortable with talking openly about death and dying, and preparing patients and significant others for the end of life. However, this approach conflicts with traditional models of SLT and healthcare, which work towards positive change and progress. Within a healthcare system in which discussion of death and dying is considered taboo, the demands placed on SLTs to address these emotional and psychological issues cause conflict (DH, 2008; Riley, 2008). Certainly, such issues are gaining in prevalence in the UK, with campaigns by Dying Matters and Age UK contributing to the normalising of open and honest

discussions about death, dying and bereavement at a societal level. However, in SLT, and in palliative care as a whole, further improvements are required in order for discussion of death and dying to cease being a taboo subject (Riley, 2008) and facilitate open and effective communication around these issues. This demands specific attention particularly in cases where a patient's speech or language abilities are impaired.

Limitations and further research

This report could have been strengthened by running additional focus groups to ensure opinions expressed were not anomalous, as well as gathering data from SLTs working outside of London and the south-east of England, and SLTs working full-time with palliative patients, e.g. in a hospice environment. The authors recognise that any suggestions for change made in this report are based on a relatively small sample and that wider engagement with SLTs and associated stakeholders would enhance the strength of any recommendations. Work setting and level of experience were not a consideration in this research but may be significant in terms of expectations and resilience. Future research may consider the degree to which different workplace settings and length of experience in palliative care might affect SLTs views and beliefs.

Conclusion

There is indisputably a role for SLTs in the management of communication disorders in palliative care, albeit far broader than previous literature suggests. This is not to downplay the importance of swallowing management but rather to highlight evolution of SLT roles and to ensure that communication is not marginalised. It is suggested that the service SLTs aim to provide, which is concordant with official definitions and aims of palliative care, may not match the reality of their service, and may be hindered by lack of suitable guidelines, training, outcome measures, role definition and recognition of their role by other professionals. SLTs are keen to address these

challenges to advocate for their more established position within palliative care and wider

recognition of their potential input.

This report highlights the need for further research on the topic, in particular to address ways of

reducing conflict in the workplace, as this could lead to more effective MDT working and

consequently building more satisfying workplaces and higher-quality palliative care. Further

empirical research on the role of the SLT in palliative care communication management would

broaden the evidence base and support the development of SLT-specific guidelines for palliative

care, thereby securing SLTs' place in the palliative care team. Such research would identify current

understanding of the SLT's role, reduce the uncertainty SLTs feel about their role, and promote the

role of SLTs in palliative care.

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