


Perspectives on the role of the speech and language therapist in palliative care: An international survey

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Abstract

Background: Speech and language therapists can improve the quality of life of people receiving palliative care through the management of communication and swallowing difficulties (dysphagia). However, their role in this domain is poorly defined and little is understood about the current international professional practice in this field.

Aims: To examine how speech and language therapists perceive their role in the delivery of palliative care to clients, to discover current international speech and language therapist practices and to explore the similarities and differences in speech and language therapists' practice in palliative care internationally. This will inform professional clinical guidelines and practice in this area.

Design: Anonymous, non-experimental, cross-sectional survey design.

Participants: Speech and language therapists working with adult and paediatric palliative care populations in Republic of Ireland, United Kingdom, United States, Canada, Australia and New Zealand where the speech and language therapist profession is well established.

Method: Purposive and snowball sampling were used to recruit participants internationally using gatekeepers. An online survey was disseminated using Survey Monkey (<http://www.surveymonkey.com>).

Results: A total of 322 speech and language therapists responded to the survey. Speech and language therapist practices in palliative care were similar across continents. Current speech and language therapist practices along with barriers and facilitators to practice were identified. The need for a speech and language therapist professional position paper on this topic was emphasised by respondents.

Conclusion: Internationally, speech and language therapists believe they have a role in palliative care. The speech and language therapist respondents highlighted that this area of practice is under-resourced, under-acknowledged and poorly developed. They highlighted the need for additional research as well as specialist training and education for speech and language therapists and other multidisciplinary team members in the area of palliative care.

Keywords

Palliative care, speech and language therapist, dysphagia, communication difficulties

What is already known about the topic?

- Speech and language therapists (SLTs) can improve the quality of life of people receiving palliative care through the management of communication and swallowing difficulties (dysphagia).
- The SLT role in this domain is currently poorly defined.
- Little is understood about the current international professional practice in this field.

What this paper adds?

- Current SLT practices along with barriers and facilitators to practice were identified.
- The need for an SLT professional position paper on this topic was emphasised by respondents.
- SLT respondents highlighted that this area of practice is under-resourced, under-acknowledged and poorly developed.

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Implications for practice, theory or policy

- Respondents highlighted the need for additional research as well as specialist training and education for SLTs and other multidisciplinary team members in the area of palliative care.

Introduction

As medical care advances and the average lifespan increases, people are experiencing more frequently a gradual deterioration in health due to chronic or terminal illness, rather than an unexpected death from acute illness or infection.¹ The communication and swallowing difficulties (dysphagia) associated with these conditions present in many different ways and often have varying profiles of retained abilities and different needs depending on the nature and stage of the underlying condition.² As a result, speech and language therapists (SLTs) are increasingly adopting a palliative approach when working with people presenting with life-limiting conditions. SLTs recognise the physical, social and psychological impact that having a communication or swallowing impairment can have on people with life-limiting conditions and their families. Therefore, the aim of the SLT in palliative care (PC) is to 'affirm life and minimise the complications of life limiting disease' (p. 304).³ It focuses on supporting the person and his or her family in meeting the goals for daily activities, participation and quality of life⁴ and to live as actively as possible until death.⁵

Tomblin and Mueller⁶ (p. 109) advise that SLTs' 'knowledge of feeding/swallowing, cognition and communication make them uniquely qualified' to work in the area of PC. They also suggest that despite the relatively few publications that address the specific roles and responsibilities of SLTs in PC, it is clear that SLTs often 'provide pivotal input regarding communication and swallowing' that can greatly affect the quality of life of people receiving PC (p. 108).⁶ However, as Eckman and Roe⁷ (p. 179) emphasise, notwithstanding the increasing number of SLTs working in the area of PC, 'there is a need for education and research to support service development and understanding of their role'. It is necessary to acknowledge that although Eckman and Roe's⁷ article is a decade old, their observations remain an ongoing issue today, highlighted again more recently by Roe and Leslie,³ Pollens⁴ and Tomblin and Mueller.⁶ It is now timely to examine this area further.

The starting point for developing education and research is to examine the current practice internationally as it is hypothesised that this SLT role has evolved in a largely unplanned response to clinical need. There is limited literature available beyond clinical opinion or isolated case studies in which the current practices of SLTs in PC internationally have been discussed. Consequently, there is considerable uncertainty and an absence of clarity regarding what is appropriate and ethical SLT involvement with this

client group. Furthermore, there is limited professional guidance available to SLTs to regulate practice in PC as well as the lack of support from SLT professional bodies for clinicians who are working with this client group. It is suspected that some SLTs may perceive that they do not have a specific role in this area. As a result, service delivery and expansion of clinical SLT services in PC are often piecemeal, hampered and confounded by the lack of clear SLT professional position papers despite the fact that many SLTs are practising in this area internationally.

The aim of this study is to examine how SLTs perceive their role in the delivery of PC to clients, discover how SLTs are currently practising internationally in this area and explore the similarities and differences in international SLTs' practice in PC in order to inform professional clinical guidelines.

Methods

A descriptive research methodology was chosen, as it best matched the research aims and allowed the researchers to observe and describe the present existing conditions and behaviour without influencing them in any way.⁸ An anonymous, non-experimental, cross-sectional study was adopted as it allowed the collection of 'opinions, knowledge and data from a number of people in a systematic uniformed way' (p. 40).⁹

The Tailored Research Method¹⁰ was adopted when designing the survey to maximise response rates.⁹ A review of the literature was completed in order to identify the current, published findings and opinions regarding the role and practices of SLTs in PC internationally. This was then combined with the previous clinical experience of the researchers as well as that of SLT colleagues. In this way, it was ensured that the survey was seeking answers to questions on all topics relevant to the role and practices of SLTs in PC.¹¹ Survey Monkey (<http://www.surveymonkey.com>) was used to create and disseminate the open survey. Following a pilot of an initial draft of the online survey on two SLTs who matched the inclusion criteria of the study but who did not participate further in data collection, minor amendments were made to the survey questions.

The survey contained 26 questions requiring the respondent to give a 'yes/no/not sure' response or indicate agreement with a series of statements (Table 1). There was just one mandatory question that sought information on whether the respondent was currently working with people

Table 1. Survey questions.

Section 1: definitions of palliative care and the role of the SLT	
1	For the purpose of this survey palliative care is defined as follows: 'an approach that improves the quality of life of individuals and their families facing the problems associated with life threatening illness, through prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'. (p. 84) ¹² Does this definition summarise your understanding of the term palliative care?
2	Please state your level of agreement or disagreement with this statement: SLTs have a role in the care of individuals with communication, feeding and/or swallowing difficulties who are receiving palliative care.
3	Please state your level of agreement or disagreement with the following statements from Pollens ¹³ : 'The roles of the SLT in palliative care include ...' Providing consultation to patients, families and members of the palliative care team in the areas of communication, feeding and swallowing function. Assessing and managing communication difficulties in order to support the patient's role in decision-making, to maintain social closeness and to assist the patient in fulfilling goals. Assessing and managing feeding and swallowing difficulties in order to improve patient comfort and eating satisfaction, and promote positive feeding interactions. Communicating with members of the palliative care team in order to provide and receive input related to overall patient care.
4	Do you believe this role is acknowledged by: The professional organisation to which you are affiliated, for example, RCSLT, IASLT and SPA. Your government healthcare funding body, for example, HSE, NHS and Medicare.
Section 2: current practices	
5	Are you currently delivering speech and language therapy services to individuals who are receiving palliative care services or facing life-limiting illness?
6	How much of your clinical time do you spend on working individuals who are receiving palliative care or facing life-limiting illness?
7	Who are you currently providing speech and language therapy palliative care services to?
8	Please indicate the populations that you deliver a palliative care service for.
9	In what context are you primarily involved in palliative care?
10	Which of these statements best describe the SLT involvement in the palliative care team in your setting? The SLT provides a consultative role ONLY, that is, makes general recommendations to the palliative care team regarding communication, feeding and swallowing in the palliative care population but DOES NOT provide a service to individuals and/or their families. The SLT receives referrals from the palliative care team for communication, feeding and swallowing assessment and management and also provides the team including the individual and/or carer with general recommendations regarding communication, feeding and swallowing in the palliative care population. The SLT screens all individuals receiving palliative care who are at risk for communication, feeding or swallowing difficulties and also provides the team, the individual and/or carer with general recommendations regarding communication, feeding and swallowing in the palliative care population. None of the above/other (please specify)
11	Are you satisfied with the level of SLT involvement in the palliative care team in your setting?
12	What aspects of care are you involved in when caring for individuals receiving palliative care? Feeding and swallowing management, for example, direct intervention with client involving diet modification and changing posture Communication management Advice on oral hygiene Saliva management Education of the patient, their family and/or the MDT regarding communication and swallowing difficulties Other (please specify)
13	Please describe how frequently you are involved in each of these areas of practice when caring for an individual receiving palliative care directly or indirectly through their family/carers? Feeding and swallowing management, for example, direct intervention with client involving diet modification and changing posture Communication management Advice regarding oral hygiene

(Continued)

Table 1. (Continued)

	Saliva management
	Education of the client, their family, carers and/or the MDT regarding communication and swallowing difficulties
14	Please rank your level of confidence in providing speech and language therapy services to people receiving palliative care presenting with the following difficulties:
	Feeding and swallowing difficulties
	Communication difficulties
	Irregularities in saliva production/management
	Oral hygiene needs
15	Are you a member of a palliative care MDT?
16	Who are members of the palliative care team in your setting?
17	Which palliative care team members do you work with most frequently?
18	What do you feel are the barriers to effective practice in this area?
19	What do you feel would facilitate effective practice in this area?
	Section 3: training, skills and the future
20	Where did you develop your skills in working with this client group?
21	Please state your level of agreement or disagreement with the following statements regarding the way forward for SLT involvement with this client group:
	SLTs should have no involvement with this client group as it is beyond their scope of practice.
	SLTs should adopt a more active role in the management of this client group with the delivery of SLT services in hospices and so on.
	SLTs should be included as core members of the palliative care MDT.
	SLTs need to develop guidelines on their scope of practice in this area.
	SLTs need to introduce undergraduate training in the area.
	There is no need for further action.
	Section 4: demographic information
22	In what country did you complete your undergraduate SLT training?
23	How many years of experience do you have working as an SLT?
24	In what country are you based?
25	In what type of setting are you currently practicing?
26	Have you undertaken further education in palliative care since graduation?

SLT: speech and language therapist; MDT: multidisciplinary team; RCSLT: Royal College of Speech and Language Therapists; IASLT: Irish Association of Speech and Language Therapists; HSE: Health and Safety Executive; NHS: National Health Service.

receiving PC. This allowed for adaptive questioning based on the participant's response. The survey questions explored the role of the SLT in PC, the current practices of SLTs working in PC and respondent demographics. The questions in the survey were not randomised.

Participants

The target population was SLTs in the Republic of Ireland, New Zealand, United Kingdom, Australia, Canada and United States. These countries were chosen as they have well-established SLT services and active professional SLT bodies. Purposive and snowball sampling were used to recruit participants.⁸ Inclusion criteria for the study required that each respondent must be a professionally qualified SLT, proficient in English and with Internet access to complete the survey.

The researchers judged that the best way of recruiting participants was to involve the SLT professional bodies as well as using international SLT contacts. Gatekeepers

(including the chairpersons of professional bodies) provided potential participants with information about the study and the electronic survey link via email.

Participants self-selected from the information provided to them in the participant information email. Consent was implied by the participants when they completed the survey. The survey was anonymous. However, if participants identified themselves during the course of the survey, the data were anonymised and were not reported in a way that identified the participant. Data protection legislation was adhered to throughout the course of the study. Duplicate entries were avoided by preventing users with the same IP address access to the survey twice. However, no record of these IP addresses was kept by the researcher to protect anonymity.

Data analysis

Survey data were collected between February and March 2013. The data obtained from the survey were downloaded

from Survey Monkey and entered into an Excel spreadsheet. The data collected were analysed using descriptive statistics. The data collected from comment boxes and open questions in the survey were analysed qualitatively using thematic analysis. This enabled the researcher to identify emerging themes and understand the respondents' opinions, concerns and suggestions, in particular those that had not been prompted by the survey's questions.¹⁴ All surveys, including those that were not fully completed, were analysed.

Results

Overall view and response rates cannot be calculated due to the survey design and website functionality. In total, 322 SLTs from the Republic of Ireland, United Kingdom, Canada, Australia, United States and New Zealand responded to the survey, and 305 of these completed the survey. This amounts to a completion rate of 94.7%. The survey has a confidence interval/margin of error of ± 5.46 (95% confidence level).

Profile of participants

The results suggest that the majority of respondents delivering a PC SLT service work with people with advanced dementia (71%), cancer (78%) and progressive neurological illness (79%), with most of these respondents working in acute (51%) or community (18%) settings. Respondents reported limited core membership of PC multidisciplinary teams (MDTs), and only two-fifths (94/234) said they are satisfied with the level of SLT involvement in PC in their work setting. SLTs also indicated that they primarily develop skills in PC through clinical experience and learning from senior and other professional colleagues.

The role of the SLT in PC

Almost all (92%) of the SLT respondents agreed with the World Health Organization's¹² (p. 84) definition of PC and 96% believe that SLTs have a role in the care of people receiving PC or who are facing life-limiting illness. The majority agreed that this role includes assessing and managing swallowing difficulties; assessing and managing communication difficulties; educating the person receiving PC, their family and the MDT regarding communication and swallowing difficulties; and participating in overall patient care through MDT involvement.

Some respondents provided additional comments highlighting a range of important issues and considerations regarding the role of the SLT in PC. These qualitative data were analysed thematically. Themes included the importance of dignity, quality of life, comfort and MDT involvement in PC; how the SLT role with this client group is determined on a case-by-case basis; and the frequency of

indirect management, for example, education and ethical decision-making surrounding non-oral nutrition.

Comments provided in the survey emphasise that SLT respondents want clarification on their role in order to inform practice and improve understanding. For example, one respondent commented that SLTs '... absolutely have a role but fear it is not understood or even appreciated'. Another respondent commented that while working with a person during the last days of their life

I often get confused about our role here. Sometimes I think – am I actually adding burden to the precious time they have left and I have to think very hard about what I am adding – how/am I actually improving this person's quality of life at the end of their life or am I adding unnecessary burden with difficult decisions such as feeding at risk – I still have a lot to learn.

Barriers and facilitators to SLT practice in PC

The identified barriers and facilitators to effective SLT practice centred around five key themes. First, resource availability was identified as a barrier to SLT practice in PC, as highlighted by this respondent who comments that SLTs require the following: 'dedicated positions or time allocated; resource kits for clinicians and clients/family; educational materials for clinicians; a hub for evidence based practice information'. *The need for PC MDT involvement* was also identified as a theme, as highlighted by this respondent's comment 'I have to push my role as SLT involvement does not seem to be automatic – I don't think many other team members realise what we can offer'. *Another theme identified from the respondents' comments was the need for additional research* in the area with respondents indicating that they want 'wider understanding, and potentially further case study or other research regarding the role of SLTs in the palliative care setting'. *Finally, the respondents indicated that they would welcome the development of practice guidelines* ('development of formal guidelines for SLT role in palliative care') and education, training and support ('increased education about the SLT role and thus increased collaboration with other palliative care team members in order to provide support to families in a more multidisciplinary way rather than separate disciplines working independently').

In summary, respondents delivering a PC SLT service at the time of the survey reported that they believe SLT involvement in PC to be within the SLT professional scope of practice. They perceived that SLTs need to be more involved in the management of people receiving PC but that SLT professional policies and guidelines are required to guide this practice. Respondents concluded that further action is necessary to improve SLT involvement in this area.

Discussion

The findings from this survey suggest that SLTs are uncertain about the extent of their role in PC and believe that SLT services are under-developed, under-resourced and under-supported. There was no difference in these sentiments internationally. Interestingly, many SLTs from around the world emailed the researchers following the survey to express their support for further research and clinical direction in PC. Some respondents were working with children receiving PC, and while the survey did not explore this caseload specifically, it is clear that the SLT role is even less well developed with this population in many countries surveyed.

The survey confirmed that the SLT role in PC is perceived as frequently misunderstood or unrecognised at facility, regional, national and international levels. This is of professional concern, given the significant contribution that SLTs can and do make to the management of communication and swallowing impairments and disability in people with PC.

From these survey results and the available published literature, the researchers propose four key areas where action is required to further the development of SLT involvement in PC. These include (1) epidemiological research on communication and swallowing difficulties in PC to confirm the nature and extent of impairments in communication and swallowing in this population; (2) the development of practice guidelines for SLTs in PC internationally; (3) education of MDT members and other key stakeholders on the contribution of SLT in PC and (4) specialist SLT service development coupled with specialist education and training of SLTs as well as other members of the MDT.

This survey was not without its limitations. For example, the survey was only available online for a limited amount of time due to time constraints on the study. While frequent comment boxes provided respondents with the chance to elaborate on responses, focus groups would have afforded the opportunity to expand the discussion and facilitate a more in-depth exploration of themes. However, the survey succeeds in providing a preliminary 'bird's-eye' view of international PC practice.

As SLTs we have chosen to examine our role and scope of practice in PC. It is unclear whether other MDT members also encounter the lack of recognition in this area of practice and whether this indeed hampers service delivery in specific contexts. This article serves to provide a starting point for debate, therefore, not only within our own SLT profession but also for other MDT members.

Declaration of conflicting interests

The authors declare no conflict of interest.

Ethical approval

Ethical approval for this research was obtained from the Faculty of Health Sciences Research Ethics Committee, Trinity College Dublin in February 2013

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