

**Critical Review:
What role does the Speech Language Pathologist play in adult palliative care settings?**

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This review examined the research available on the role of Speech-Language Pathologists in adult palliative care settings. The articles reviewed included a scoping review of the literature, a survey study, semi-structures interviews, and commentaries.

Introduction

Palliative care refers to a philosophical service delivery model that improves the quality of life of patients and their families facing life-threatening illness (WHO, 2002). A patient enters palliative care once they have received the diagnosis of a life-limiting illness. Palliative care encompasses: 1) the approach to care taken by the service providers, 2) End-of-life (EOL) care (in the last 3 months of life), 3) Hospice care (in the last few weeks/days of life), and, 4) Bereavement care of the families. The former definition of terms will guide the discussion in the article, while acknowledging some literature uses the terms: end-of-life, palliative or hospice, synonymously. (Toner & Shadden, 2012)

Brief History of Palliative Care

The field of palliative care emerged in the late 1960s, and its development was bolstered by the birth of the modern hospice (Saunders, 2001). The work of Dame Cicely Saunders was instrumental in shining a light on the breadth of end-of-life (EOL) needs of patients with advanced malignant disease (Clark, 2007). By introducing the concept of “total pain”, Dame Saunders outlined that suffering encompassed the pain related to the pathophysiology of the disease, but that it was also modified by the psychosocial, existential and spiritual aspects of suffering. This view of suffering implied a need for “total pain control”, which reached beyond caring for the patient, and included addressing the suffering of families and caregivers (Saunders, 2001).

Dr. Balfour Mount, founder of the first Palliative Care Service at Montreal’s Royal Victoria Hospital, coined the term “palliative care”, in the mid-1970s (Clark, 2007). Dr. Mount chose the term palliative care because its etymology implied “to improve the quality of”. Since, palliative care has become synonymous with the provision of physical, social, psychological, and spiritual support to patients with life-limiting illness. The provision of such holistic care requires a multidisciplinary team, also called a palliative care

team, to provide comprehensive care for the patients’ and families’ needs (Cherny & Christakis, 2011).

Speech Language Pathology and Palliative Care

As palliative care (PC) implies a shift away from curative measures, but it does not imply the cessation of rehabilitation, rather a change in focus from a curative model to a supportive model focused on quality of life (Roe & Leslie, 2010). This reconceptualisation of rehabilitation is required to frame the discussion for this review as it pertains to the role of the Speech Language Pathologist (SLP) within the PC model. Traditionally, the SLP has a habilitative or rehabilitative role to play in a patient’s health journey. The role of the SLP in PC highlights the conundrum of what defines rehabilitation once functional outcomes cannot be ameliorated (Chahda, Mathisen & Carey, 2017).

Within the context of the emerging field of PC, the purpose of the critical analysis reported in this review was to examine available literature informing the role of SLPs in palliative care for the adult population, with regards to communication, cognition and swallowing. Empirical evidence is expected to be minimal, as ethical and legal limitations restrict rigorous quantitative research. Thusly, much of the observational literature will consist of reports of current practice, and opinions related to working with this population. This article will help to determine the potential contribution of SLPs to the PC team, and to the palliative patient and their family.

Objectives

The primary objective of this paper was to critically review the literature to determine what role(s) SLPs currently play in adult palliative care settings, with regards to communication, cognition and swallowing. The secondary objective was to identify potential barriers and facilitators to the involvement of SLPs on the palliative care team.

Methods

Search Strategy

Online databases searched: PubMed, Scopus, Cinahl and ASHA journals. Using key words: [(Palliative care) OR (End of Life care) AND (Speech Language Pathologist) OR (Speech Language Therapist) AND (role) AND (Communication) AND (Dysphagia) OR (Swallowing) And (Cognition)].

Selection Criteria

The criteria for including studies were i) that subjects should be 18 years of age or older; ii) considered “palliative”, or “end of life”; iii) displaying dysphagia, communication or cognition impairments; iii) articles investigated the role of SLPs on palliative care teams; iv) were published after 2003, v) available through the Western’s online database, vi) written or available in English. Studies were excluded if: vii) articles focused on a specific population (e.g. Amyotrophic Lateral Sclerosis); viii) articles focused on palliative care curriculum; ix) articles focused legal and ethical in specific terms.

Data Collection

Papers included in this review were: one cross-sectional survey, one scoping review, five commentaries, and one semi-structured interview.

Results

Survey Design

A survey design is an appropriate and cost-effective way to collect objective information from a large population. However, survey responses can suffer from bias related the interpretation of the questions, participant expectations, and often fail to provide generalizable data.

O’Reilly & Walshe (2015) conducted a survey study to explore: how speech and language therapists (SLT) perceive their role delivering palliative care (PC), to discover current international SLT practices, and to explore international similarities and differences in service delivery.

The study’s survey topics were determined following a literature review and the authors’ personal clinical experience. The online survey was designed using the Tailored Design Method (Dillman, 2011) to take into account features of the survey situation and to reduce survey error. Inclusion criteria were outlined, as was the anonymity protocol. An initial draft was piloted to 2 SLTs who matched the inclusion criteria, leading to minor amendments. The mixed format cross-sectional survey used purposive and snowball sampling to recruit

participants over the course of two months, from 6 English-speaking countries, selected due to the presence of active SLT professional bodies. A total of 322 SLTs responded to the survey. Responses were analyzed descriptively and using thematic analysis.

The study’s methodology included no view and/or response rates calculations. No statistical analyses were performed on the data collected, which is not appropriate given the design and the questions asked by the researchers. Descriptive reports of the data suggest that 96% of respondents perceived that they play a valuable role on the PC team. The study identified that half of SLTs working in palliative settings work in acute settings, and that 60% of them were dissatisfied with the level of SLT involvement on the PC team in their work setting. The respondents identified 4 barriers to effective SLT practice in PC: resource availability, lack of awareness regarding the role of the SLT in PC on the palliative team, lack of available research, and lack of practice guidelines as well as education/training/support to provide support to families in a multidisciplinary way.

Due to its methodological shortcomings, this article suggests equivocal evidence, but provides a valuable perspective from SLTs working in the field, particularly in identifying existing barriers to service provision; namely that the role is under-resourced, under-acknowledged and poorly developed.

Scoping Review

A scoping review is a type of literature review that is effective in exploratory research, particularly to map key concepts and to identify gaps in literature. Its scope is broader than a systematic review and is not required to present scientific evidence.

Chahda (2016) conducted a scoping review examining the role and practice of SLPs in adult palliative care. Search terms were relevant and clearly specified. A set of 13 articles were reviewed by a team of 3 raters. Procedures for how articles were evaluated was well specified and coded thematically. Results revealed that there is growing recognition that an interdisciplinary team is key to optimal EOL care. The authors highlight the paradigm shift required for SLPs in palliative care-away from (re)habilitation with curative focus.

The authors find that the literature is supportive of SLPs being part of palliative care team, particularly with regards to communication and dysphagia management as patients approach EOL. The article outlines that SLPs play a crucial role in supporting person’s participation in discussing plans for EOL care. They also call on

academic institutions to include foundational knowledge on palliative care as part of the SLP curriculum.

Overall, this paper provides highly suggestive evidence that SLPs have a role in palliative care, and that there exists a need for further research in order to develop protocols. The authors are compelling in their plea for working SLPs to collect and publish about their practical procedures in palliative care to develop the evidence base

Commentary Articles

Given the emerging nature of this topic, reviews of the literature can provide valuable information as to how SLPs may be involved in palliative care by using selected research to inform practice. These articles should be interpreted with caution because there is often a lack of critical analysis, and a considerable risk for bias in the article selection, and the interpretation.

Pollens (2004) discussed the role of the SLP in the palliative hospice setting. Robin Pollens is an expert in the field and one of the earliest advocates for SLPs working in palliative settings. In this oft-cited paper, she provides a literature review and uses anecdotal case histories to illustrate what she has outlined as the four primary roles of the SLP in hospice care. These roles include: consulting with the patient/family and with the rest of the medical team regarding issues surrounding communication, swallowing and cognition, delivering strategies to support communication and to assist the client in the fulfillment of end-of-life goals, assisting in optimizing feeding, and communicating with members of the hospice team to provide and/or receive input related to the patient's care.

The author outlines potential goals for the SLP to set for the patient's communication and feeding. She also details responsibilities that the SLP is best suited for when communicating with the patient/family and with the interdisciplinary team. The author calls for further research to analyze what service delivery is being provided by the SLPs working in hospice and to develop models for facilitating ancillary services in order to strengthen the delivery of palliative care for patients and families.

This article offers highly suggestive arguments for the benefits of including the SLP on the palliative care team. Of particular interest are her arguments for pressing need for SLPs to advocate for their worth on the PC team.

Groher & Groher (2012) discussed the factors related to the role of the SLP and the ethical challenges that they may confront in providing swallowing

management to patients nearing the EOL. They include 3 case scenarios to illustrate the need for informed decisions to occur as a collaborative effort between medical professionals, the family and the patient. The authors discuss the options for tube feeding, common reasons for placing a feeding tube, aspiration pneumonia, elements of a Modified Barium Swallow, and medical ethics surrounding palliative care.

The first author is a well-known researcher in the field who has published extensively about dysphagia diagnosis and management. In this paper, the authors focus their attention on the factors surrounding decision-making for patients in EOL care who are unsafe for oral alimentation, particularly with regards to the use or denial of tube feeding. In light of the lack of clear guidelines for long-term feeding tube placement, the authors suggest consultation with the patient's or family's wishes, followed by conversations outlining the medical, and nonmedical, risks/benefits for the patient. For intubated patients at the EOL, authors counsel SLP's to consider suggesting small quantities of the patient's favourite food or drink. When ethical dilemmas arise, the authors recommend enlisting the support of the PC team or ethics committee to provide an unbiased review of the medical and nonmedical risks associated with tube feeding.

The paper sheds light on the debates that exist in the literature, e.g. the use of thickened liquids as a management strategy to protect the airway. The authors caution that swallowing management in the EOL care must be determined on a case-by-case basis, as there are too many individual factors at play to be able to create clear-cut guidelines for feeding.

This article provides highly suggestive evidence regarding the importance of SLPs communicating with team care providers when assessing and developing recommendations pertaining to dysphagia or feeding strategies for palliative patients.

Pollens (2012) discussed the ways for SLPs to effectively contribute to the palliative care team. The author is a pioneer in the field, and this is a follow-up to her 2004 article that continues her discussion regarding how SLPs can become more integrated members of the PC team. In the article, Pollens outlines recommendations, and includes case discussions to apply her concepts.

In order to actively participate on the PC team, the SLP is urged to integrate their contribution more effectively into the work of the PC team by describing the communication consults in relation to improved palliative care outcomes to support mutually established

patient care goals. Additionally, the SLP should remain informed about the holistic clinical status of the patient while offering quality communication and swallowing care to patients and their families. The SLP in this setting should remain mindful of compassion fatigue and implement strategies for self-care that include developing a support system in one's work setting and advocating for continuing education about EOL care. Lastly, the author implores SLPs to educate others about the contribution of the SLP on the PC team by presenting to community, hospice settings and academic institutions to increase awareness of the role of the SLP, and to stay current in their knowledge.

Author encouraged advocacy for the SLPs clinical focus to change to a palliative care participation outcome, as opposed to impairment based outcome. The cases that are included offer emphasis to her arguments.

This article provides suggestive evidence regarding the role of SLPs in palliative care. It offers useful tools for SLPs to refer to in order to advocate for their position on PC teams. The author provides practical recommendations for communication and dysphagia consults.

Roe & Leslie (2010) discussed the roles that an SLP may play in palliative care. In this commentary article, the authors who are experienced in the field define the terminology associated with rehabilitation in the palliative care setting. They also highlight the challenges that can impact the SLP's service provision, including the intricacies of the process of discharge, and the support available to clinicians working with this population.

The authors suggest that the contribution of SLPs to the PC team is for symptom control, patient empowerment, and to minimize the impact of swallowing and communication difficulties on quality of life. According to the article, SLPs working in palliative care must first determine a person's suitability and commitment to the rehabilitation process. Factors that determine suitability include: the patient's acceptance of their disease, their expectations of therapy, and life priorities. The authors suggest that goals must be set at the outset of therapy, and that these goals should respect the patient's functional wishes, as well as their optimal level of functioning and comfort. They suggest that a crucial component to the SLP's role in palliative settings is to recognize when to step back, and to allow other more suitable professionals to take over.

The article discussed the benefits of beginning the process of discharge at the outset of the SLP's involvement. This conversation with the patient and

their family regarding potential changes in priorities that may accompany the disease's progression, may serve to prepare them for an eventual decrease in the clinician's involvement.

This article provides suggestive evidence for the importance of the SLP's role within a multi-disciplinary PC team. The authors provide helpful guidelines for determining patient suitability for therapy.

Semi-Structured Interviews are a common measure to gather qualitative data. They are typically accompanied by thematic analysis to generate key themes. Factors such as: time limitations, intra-interviewer inconsistencies, and the complexity of subject matter may influence the quality of the generated information. The findings are not generalizable, but reveal the experience of a sampled population.

Hawksley (2017) conducted semi-structured interviews and a follow-up focus group with 12 SLTs to discuss the core beliefs, values and expectations of SLTs working in palliative care settings. The author focused on the SLTs' role in supporting patient communication.

All 12 female participants self-selected to participate in the interviews, their experience and age varied. All but 1 worked in the public sector- in acute, rehabilitative and community settings, with various populations. Each interview was 55-90 minutes and the data was analyzed using an inductive thematic analysis (Braun & Clarke, 2006). The thematic analysis was detailed. For the second phase of the study, 5 of the original participants self-selected to attend a focus group to discuss the identified themes. Limitations of the methodology were outlined, including the lack of random sampling. Data analysis for the focus group also used the inductive thematic analysis, and data was triangulated against the individual interview data to ensure that themes correlated between data sets.

The result of the study revealed four themes: conflict, pioneering, justifying the SLT's role, and dealing with death. Conflict was the overarching theme, included workplace conflict, and emotional conflict. Pioneering referred to the SLT's responsibility to advocate and to adapt the guidelines of traditional practice to the palliative care model. The authors outline that palliative care-specific guidelines are needed to improve the SLT's ability to set goals and meet targets. The authors speculate that these guidelines would increase the SLT's confidence working in this sector, ameliorate inter-professional awareness of their role, and improve integration onto the palliative care team.

Despite its methodological limitations, this article provides highly suggestive evidence regarding the roles that SLP currently play on the PC team with regard to communication.

Discussion

Overall, the articles reviewed in this paper provide suggestive arguments that SLPs have a role to play on the PC team because of their training in communication and dysphagia management. The papers agree that the current membership of SLPs on the PC team is largely limited to a consultative role in acute care settings, consisting predominantly of swallowing management.

The literature suggests that SLPs are confident that their expertise is well suited to PC settings. However, there is a lack of guidelines and protocols to inform their work, particularly with regards to communication management (Chahda, 2016). The literature suggests that these guidelines and protocols need to be flexible to be adaptable to the scope of roles that SLPs play in PC settings, to the heterogeneous presentation of patients with life-threatening conditions, and in order to respect the individual needs of a patient and their family. The presence of guidelines/protocols would improve the SLP's confidence working in this area by outlining appropriate goals, and targets for communication and swallowing management.

The articles reviewing the SLP's role(s) in swallowing management agree that it involves formulating the patient's plan of care based on risk assessment for aspiration, therapeutic recommendations on safe feeding (according to bolus type, delivery method, posture and/or feeding technique), and frequent reassessment to monitor as the condition changes (Groher & Groher, 2012). The literature highlights that a significant role of the SLP in the EOL care is educating the patient and family regarding the natural physiological changes that lead to a decrease in appetite and hydration needs. The ethical responsibilities of swallowing management are considered significant and the literature suggests consultation with the ethics or a legal team if dissent arises on the PC team, particularly with regards to swallowing management.

According to the literature, the role(s) of the SLP in communication management comprises of: supporting a person's participation in discussing plans for their EOL care with their families and the PC team, developing strategies to maximize their communicative functioning (including augmentative and alternative communication), and educating family and members of the PC team regarding the patient's communicative needs. Another key role that the SLP can play is to

foster advocacy in the patient, and their family. The timing of the introduction of the SLP's services to the patient was cited as a barrier to rehabilitation (Hawksley, 2017). To counter this, the literature outlines that the SLPs be present throughout the palliative journey from the time of diagnosis, not just in the final stage of life (Pollens, 2012). However, poor inter-professional understanding of the SLP's role in palliative care leads to a lack of referrals, until swallowing needs emerge in the EOL.

The articles identify that the dearth of qualitative and quantitative research pertaining to the benefits of SLP in palliative rehabilitation is a considerable factor to the lack of inter-professional awareness. As such, it is difficult to offer compelling evidence for the positive impact that an SLP might have on the PC team, and on the improved satisfaction with the palliative services received by the patient and their families.

In order to become better integrated within the PC team, the literature suggests that SLPs educate and advocate about their worth on the PC team within diverse health care settings, and in the community at large. It is important to note that the limitations faced by SLPs in palliative care (e.g. lack of referrals, time, resources, training) are also identified as barriers for other professions working in palliative medicine (Hawksley, 2017). The SLP's role in communication and dysphagia in palliative care were discussed in the appraised literature, but information was particularly scarce in relation to the SLP's role in assessing and treating cognition. If SLPs want to advocate for their abilities to help palliative patients and their families with decision-making, further research needs to be conducted in this particular area.

The major limitation of these articles was the lack of evidence and research. However, the uniformity in message and tone from experts does point to an overall compelling argument for the presence of SLPs on PC teams. It must be cautioned that the perspectives offered from these articles are biased, as their authors are SLPs who have a vested interest in the topic at hand. Research should also consider when/if SLP involvement with a palliative patient may be contraindicated.

Conclusion

The body of literature reviewed unanimously supports the addition of SLPs to the PC team, albeit lacking empirical evidence for determining the benefits for the patient, family and/or other professionals. Further research should continue to clarify the role of the SLP in swallowing, communication and cognitive management within the context of palliative rehabilitation. It may

behoove further researchers to identify barriers to SLPs collecting data on PC teams in order to find ways to counteract them.

According to the gaps in the current literature, more research is required to determine the effect(s) of the presence of the SLP on the patient/families' level of satisfaction with care, and/or on the PC team's level of satisfaction with their ability to provide person-centered care.

Given the SLP's scope of practice, they appear well equipped to be included on multi-disciplinary PC teams from diagnosis onwards. However, to increase the SLP's confidence working in PC, to ensure consistency and best practice service delivery, regulatory bodies throughout the world must develop comprehensive clinical practice guidelines and protocols.

Clinical Implications

SLPs working in this field are equipped with the knowledge to increase the patient and family's quality of life at a time of great upheaval. SLPs working in the area are urged to publish regarding effective multi-disciplinary practice, and examples of innovative practice in PC. Institutions that provide palliative care are encouraged to ensure that their PC staff receives sufficient psychological support to counter the high emotional demands of the work, and to foster self-reflective practice. SLPs working in PC settings are urged to advocate for their role with respects to swallowing, and communication, while explaining the research limitations imposed by the ethical considerations that are specific to this population.

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