

Journal of Clinical Practice in Speech-Language Pathology

Volume **17**, Number **2** 2015

Aged care

jepslp.

In this issue:

Challenges to communication management in aged care

Speech pathology services following TBI

Volunteer-led aphasia groups

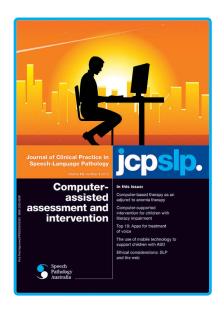
The future of speech pathology in aged care

Being prepared for working in palliative care

Educating a future aged-care resource

'Doing good' in end-of-life care





Electronic copies of JCPSLP

Speech Pathology Australia members are able to access past and present issues of *JCPSLP* via the Speech Pathology Australia website

www.speechpathologyaustralia.org.au/publications/jcpslp

Electronic copies of the full journal or individual articles are available to everyone (members and non-members) at a cost by emailing

pubs@speechpathologyaustralia.org.au

or by completing the form available from the Speech Pathology Australia website



Speech Pathology Australia

Level 1 / 114 William Street, Melbourne, Victoria 3000 T: 03 9642 4899 F: 03 9642 4922 Email:

office@speechpathologyaustralia.org.au Website:

www.speechpathologyaustralia.org.au ABN 17 008 393 440 ACN 008 393 440

Speech Pathology Australia Board

Gaenor Dixon

President

Robyn Stephen

Vice President Communications
Relinda Hill

Vice President Operations Chyrisse Heine

Brooke Sanderson

Tim Kittel

Asher Verheggen

JCPSLP Editor

David Trembath c/- Speech Pathology Australia

Editorial Committee

Chris Brebner
Jade Cartwright
Natalie Ciccone
Catherine Gregory
Deborah Hersh
Elizabeth Lea
Samantha Turner

Copy edited by Carla Taines Designed by Bruce Godden, Wildfire Graphics Pty Ltd

Contribution deadlines

Number 1, 2016

- 1 August 2015 (peer review)
- 1 August 2015 (non peer review) Number 2, 2016
 - 1 December 2015 (peer review)
 - 1 December 2015 (non peer review)

Number 3, 2016

13 April 2016 (peer review)

13 April 2016 (non peer review)

Advertising

Booking deadlines Number 3, 2015 17 August 2015 Number 1, 2016 1 December 2015 Number 2, 2016 6 April 2016 Please contact the Publications Officer at Speech Pathology Australia for advertising information.

Acceptance of advertisements does not imply Speech Pathology Australia's endorsement of the product or service. Although the Association reserves the right to reject advertising copy, it does not accept responsibility for the accuracy of statements by advertisers. Speech Pathology Australia will not publish advertisements that are inconsistent with its public image.

2015 Subscriptions

Australian subscribers – \$AUD106.00 (including GST). Overseas subscribers – \$AUD132.00 (including postage and handling). Institutional rate – \$AUD330 (including GST). No agency discounts.

Reference

This issue of *Journal of Clinical Practice* in *Speech-Language Pathology* is cited as Volume 17, Number 2, 2015.

Disclaimer

To the best of The Speech Pathology Association of Australia Limited's ("the Association") knowledge, this information is valid at the time of publication. The Association makes no warranty or representation in relation to the content or accuracy of the material in this publication. The Association expressly disclaims any and all liability (including liability for negligence) in respect of use of the information provided. The Association recommends you seek independent professional advice prior to making any decision involving matters outlined in this publication.

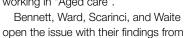
Copyright

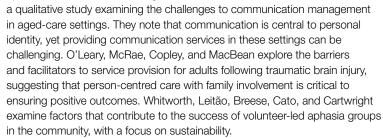
©2015 The Speech Pathology
Association of Australia Limited.
Contributors are required to secure permission for the reproduction of any figure, table, or extensive (more than 50 word) extract from the text, from a source which is copyrighted – or owned – by a party other than The Speech Pathology Association of Australia Limited. This applies both to direct reproduction or "derivative reproduction" – when the contributor has created a new figure or table which derives substantially from a copyrighted source.

From the editor

David Trembath

ustralia, like many countries, has an ageing population due to a declining birth rate and increased life expectancy. This demographic change presents tremendous social opportunities, but also economic and health challenges. Speech pathologists have the expertise necessary to help ensure that people not only live longer, but do so with safe swallowing and effective communication as the basis for healthy, productive, and enjoyable lives. Accordingly, this issue of JCPSLP presents a collection of reviews, clinical insights, and research articles focusing primarily on the opportunities and challenges for speech pathologists working in "Aged care".





Three articles examine issues associated with preparing future speech pathologists for work in Aged care. Pascoe, Breen, and Cocks suggest that universities need to ensure that curricula reflect and address the growing role for speech pathologists in aged-care settings. Hewetson, Cornwell, Davern, Hill, and Hunter examine the impact of clinical placements in aged-care settings on students' knowledge, confidence, and attitudes towards with working with older people. They report positive effects on students' knowledge, skills, and attitudes following clinical placements, but a less malleable preference among students for working with younger populations. Cartwright, Sanderson, Whitworth, Oliver, and Gribble report similar results from a study in which students demonstrated improved attitudes, confidence, and collaborative practices following multidisciplinary placements in aged-care settings.

Davis and Kay present a clinical insight piece, in which they describe how a relatively small change in practice (changing medications) led to a positive service-wide impact on medication prescription within a hospital setting. Cartwright and Oliver examine the evidence for the use of non-pharmacological Montessori-based interventions for persons with dementia, highlighting the role of the speech pathologist as part of a collaborative team. Finally, Smith and Kenny present an insightful "Ethical conversations" article illustrating possible challenges and solutions to working ethically in aged-care settings.

A common theme across all articles is the importance of person-centred, multidisciplinary, evidence-based, collaborative practice. The articles leave me with the impression that the essence of working in aged-care settings is not different to that of working in other speech pathology settings. However, the opportunities are clearly many and some of the challenges unique, thus deserving and requiring a concerted, sophisticated, and enthusiastic response from our speech pathology community.



- 57 From the editor
- 58 Challenges to communication management in residential aged care Michelle K. Bennett, Elizabeth C. Ward, Nerina A. Scarinci, and Monique C. Waite
- **63** Speech pathology services following traumatic brain injury: The perspectives of health care consumers Kathryn A. O'Leary, Alastair D. McRae, Anna M. Copley, and Naomi A. MacBean
- **68** Volunteer-led aphasia groups in the community: Critical success factors in their sustainability Anne Whitworth, Suze Leitão, Melanie Breese, Louise Cato, and Jade Cartwright
- 75 The future of speech pathology in aged care: Students' confidence and interest in working with older people Ronelle Hewetson, Petrea Cornwell, Susannah Davern, Anne E. Hill, and Lucy Hunter
- **82** Being prepared for working in palliative care: The speech pathology perspective Ashleigh Pascoe, Lauren J. Breen, and Naomi Cocks
- 85 Educating a future aged-care workforce:
 Shaping positive attitudes and developing
 collaborative practice capabilities Jade
 Cartwright, Brooke Sanderson, Anne
 Whitworth, Elizabeth Oliver, and Nigel Gribble
- 91 A multidisciplinary approach to difficulty swallowing medication: An alternative to dose form modification *Emily Davis and Derek Kay*
- **94** What's the evidence? Montessori-based interventions for people with dementia in a residential aged-care setting *Jade Cartwright* and *Elizabeth Oliver*
- 98 A speech-language perspective on "doing good" in end-of-life care for people with advanced dementia Helen Smith and Belinda Kenny
- 104 Around the journals
- 106 Webwords 52: Speech-language pathology:A young profession in an ageing world- Caroline Bowen
- 109 Resource review
- **111** Top ten resources in aged care Jill Lesic

Challenges to communication management in residential aged care

Michelle K. Bennett, Elizabeth C. Ward, Nerina A. Scarinci, and Monique C. Waite

KEYWORDS

AGED CARE
COMMUNICATION
QUALITY OF LIFE
SERVICE
PROVISION
SPEECH
PATHOLOGY

THIS ARTICLE
HAS BEEN
PEERREVIEWED





Michelle K. Bennett (top), Elizabeth C.

Communication enables the expression of a person's fundamental attributes, defined as one's personhood. Communication impairment threatens personhood, reducing autonomy and independence, limiting selfexpression, and restricting interpersonal relationships. The majority of older Australians living in residential aged care experience communication impairment, yet speech pathology services provided in this setting are limited. With an ageing population and global focus on person-centred aged care, there is a need to better understand issues impacting communication management in residential aged-care settings. To facilitate this understanding, individual, in-depth, semi-structured interviews were conducted with 10 speech pathologists working in residential aged care. Qualitative content analysis revealed disparate opinions among participants about the importance and nature of communication management in the setting. Numerous factors challenging clinicians' ability to provide services for communication in the setting were discussed. Despite these challenges, the majority of participants expressed a desire to expand communication management in residential aged care.

here is a growing body of research illustrating the negative impact of communication impairment on quality of life (Cruice, Worrall, Hickson, & Murison, 2003; Hilari & Byng, 2009; Morgan, Hickson, & Worrall, 2002; Park et al., 2013; Yorkston, Bourgeois, & Baylor, 2010). The impact of communication impairment increases with ageing (Yorkston et al., 2010), presenting a significant barrier to an older person's ability to adapt to the ageing process (Lubinksi & Welland, 1997), and to preserve and express one's personhood in his or her later years (Kitwood, 1997; Lubinksi & Welland, 1997; Yorkston et al., 2010). Personhood is defined as a person's individual and unique

characteristics that are to be considered sacred and held in deep respect by others (Kitwood, 1997), Personhood provides the foundation for person-centred care, the model of care on which current national and international aged-care service provision recommendations are based (Productivity Commission, 2011; Department of Health, 2012; World Health Organization (WHO), 2002). Inherent within these service provision recommendations is an emphasis on equal and shared contribution to health care by the health professional and the service user (i.e., the older person and their significant others), and a focus on psychosocial models of service provision in addition to biomedical models. In broadening service provision beyond traditional biomedical care, person-centred care explicitly supports health services to facilitate subjective well-being and meaningful life participation (National Ageing Research Institute, 2006).

For older people residing in residential aged care, subjective well-being and meaningful life participation have been found to be largely dependent on the availability of opportunities and support to make life choices, express one's identity and sense of self, and continue to form and maintain interpersonal relationships (Ball et al., 2000). With social engagement, self-expression, decision-making, and the initiation and maintenance of relationships dependent on effective communication (Nilsson, Ekman, Ericsson, & Winblad, 1996), the provision of support for residents with communication difficulty is, therefore, essential. Past research indicates that as many as 98% of older people living in residential aged care experience communication difficulty (Worrall, Hickson, & Dodd, 1993). Further, for all residents, communication interaction has been found to be limited in both scope and frequency, to be care focused, and largely directed by care staff (Carpiac-Claver & Levy-Storms, 2007; Savundranayagam, 2014).

As specialists in the assessment and management of communication difficulties speech pathologists have the potential to take a lead role in the delivery of personcentred care, and the facilitation of resident participation and subjective well-being. At present, little is known about communication management provided by speech pathologists in residential aged-care settings. Therefore, this study aimed to explore the perceptions of speech pathologists about the importance of, nature of, and factors influencing communication management in the setting. The findings of this study may be used to inform both the current and future direction of speech pathology services in residential aged-care settings.

Method

Research strategy and participants

Permission for this study was granted by the Behavioural and Social Sciences Ethical Research Committee of The University of Queensland. With little past research in the area, qualitative descriptive methodology was chosen to explore the perceptions of 10 speech pathologists working in aged care, summarising participant perspectives using their everyday language (Sandelowski, 2000). Participants were recruited through the public directory of speech pathologists provided on The Speech Pathology Association of Australia website (The Speech Pathology Association of Australia Ltd, n.d). All participants were female, aged between 23 and 63 years (M = 46; SD =15.7), and currently working in residential aged-care settings. Participants had worked in residential aged care for between 9 months and 21 years (M = 13.7; SD = 11.3). Of the 10 participants, three worked in public speech pathology services and seven worked in private practice.

Procedure

Individual in-depth semi-structured interviews were conducted with each of the participants. A semi-structured interview guide was used to ensure key topics of enquiry were addressed across participants, while providing flexibility to enable new topics to emerge during data collection (Patton, 2002). Interviews were conducted either face-to-face or via telephone, at a time convenient to the participant. During the interview participants were asked to comment about: 1) the value of communication assessment and intervention in residential aged care; 2) the nature and frequency of communication assessment and intervention in residential aged care; and 3) education and support they had received pre- and post-qualification relevant to communication management in residential aged-care

Step	Description
Familiarisation	Each transcript was read and re-read by the first and fourth authors in its entirety, to familiarise the analysts with the data and to identify key meanings and ideas within each transcript.
Comparison across participants	Each analyst compared data across participants to identify and chart key themes and subthemes common across participants. Themes identified were inclusive to represent the data in its entirety.
Comparison across analysts	The first and fourth authors cross compared their analyses, collaborating to modify the themes and subthemes until consistency between the analysts was reached. Disagreement, overlap or ambiguity in the themes or sub-themes not resolved by the first and fourth authors was discussed with the second and third authors until consensus was reached.
Synthesis	The first and fourth authors synthesised their analyses into a single analysis containing all themes and sub-themes in their entirety.

settings. Each interview was recorded and transcribed verbatim. Interviews ranged in duration from 26 to 67 minutes (M = 39; SD = 14.1). The accuracy of the transcriptions was checked by a second analyst. All interviews were conducted by the primary author (MB).

Data analysis

Each transcribed interview was analysed by two speech pathologists, the first and fourth authors, guided by the systematic stages of the framework approach to qualitative analysis (Ritchie & Spencer, 1994). The framework approach provides transparency in qualitative analysis through the use of explicit stages, reducing bias and increasing the credibility of the interpretations (Pope, Ziebland, & Mays, 2000; Rabiee, 2004). Throughout analysis, both inductive and deductive methods of enquiry were used to address questions underpinning the research aims while remaining open to new concepts and ideas evident in the data (Pope et al., 2000; Ritchie & Spencer, 1994). An outline of the stages of analysis is provided in Table 1.

To increase the accuracy of the analysis, member checking was completed following analysis of the interview data. Member checking provided participants with the opportunity to review and comment on the interpretation of the data and to answer any additional questions arising from the analysis (Hoffart, 1991). Completed member checking documents were received from 8 out of the 10 participants, showing majority agreement with all key themes identified.

Results

Three key themes were identified: 1) there are mixed views about the importance of communication management in residential aged care; 2) communication management in residential aged care is limited and impacted by numerous factors; and 3) speech pathologists have a desire to advance communication management in residential aged care.

Theme 1: There are mixed views about the importance of communication management in residential aged care

Participants expressed disparate views about the importance of communication management in residential aged care. Some participants viewed communication management as being of high importance and "intrinsic to all needs" (Participant 1). Other participants reported a belief that communication management is not as important as managing swallowing difficulties, "communication not as important, they need to be able to communicate basic needs ... nothing we can do for severe communication difficulties" (Participant 2).

Despite expressing different views about the importance of communication management in residential aged care, most participants commented that social interaction is a key determinant of residents' quality of life. Participants emphasised the importance of taking a genuine interest in each resident as an individual, treating residents with compassion and dignity, and providing residents with opportunities for social interaction. In doing so, one participant commented, "with the knowledge speech pathologists have of different speech and language difficulties, and you know, strategies and facilitation techniques to improve social interaction, there's just enormous potential in nursing homes" (Participant 8).





Nerina A. Scarinci (top), and Monique C. Waite

Theme 2: Communication management in residential aged care is limited and impacted by numerous factors

All participants stated that referral for speech pathology services and the nature of speech pathology services in residential aged care is dominated by "swallowing". Only two of the 10 participants stated that they regularly provided communication management in aged-care settings. Participants also commented that communication management is often not a priority of aged-care management or care staff. One participant did, however, state, "I think the nursing staff prioritise communication the best way they know how" (Participant 3). Overall, most participants indicated that prioritisation of communication management in residential aged care by speech pathologists would not necessarily translate to increased aged-care sector prioritisation and support for communication management.

All participants discussed the impact of lack of funding in residential aged care for communication management. Most participants discussed a lack of support from speech pathology management to provide communication management in residential aged care, and a lack of specialist training for speech pathologists working in the setting. All participants indicated that they felt strongly that limited funding for communication management was associated with many factors including: low prioritisation of communication management by facility staff; lack of acknowledgement of communication needs in agedcare funding allocation tools; and limited awareness by residential aged-care staff about, options for and the benefits of, speech pathology services to facilitate communication. Most participants also commented that they themselves had limited knowledge regarding funding options that were available for communication management in residential aged care.

Further commenting on the support they received from their own professional management, all participants emphasised the negative impact of time and resource limitations. As a result, all participants prioritised what they were referred for – "swallowing". One participant stated "I'm aware of everything, aware of communication, but I know I've got to hurry up and get out of there you know, I'm not allowed" (Participant 1).

Many participants also indicated uncertainty about which resources and communication intervention approaches were best suited to meet residents' needs. When asked about the nature of services they would provide to facilitate resident communication if given the opportunity, many participants expressed uncertainty about the intervention approach they would use, the areas of communication they would target, and the outcomes they would hope to achieve. This uncertainty largely related to the complex nature of communication impairment among residents of aged-care facilities, including the high prevalence of cognitive impairment, degenerative disease, and comorbidity.

All participants commented that they would welcome further pre- and post-qualification training specific to facilitating communication in residential aged care, particularly for residents with cognitive-communication impairment. Many participants also expressed a desire for further training about expectations for client outcomes, reporting uncertainty about the applicability of, and means of implementing, a person-centred approach to

communication management in residential aged-care settings. All participants indicated that they were unsure about, how and whether speech pathology services should adhere to broader aged-care legislation and recommendations. When asked about current aged-care funding assessments and aged-care standards, participants made comments such as "I am not very clear on this" (Participant 1), "Again it doesn't roll off my tongue with easy familiarity" (Participant 6), "I'm not sure specifically" (Participant 7), "Not too sure, I assume it is a set of standards that health professionals must comply with in order to work with the aged population" (Participant 3).

Two participants who regularly conducted communication management in the residential aged-care settings they serviced both commented that the service they provided was highly dependent on the involvement of family members and friends of the resident. Family members and friends were noted as the primary source of referral for services to facilitate resident communication, often fund the service, and take a lead role in carrying out therapy tasks. Participant 8 discussed the role of speech pathologists in advocating for communication management in residential aged care:

If relatives around see me working with someone else they might come and have a chat with me and ask what I am doing, and say that looks great, can I ask you about my relative ... so I will have a chat with them. I think speech pathologists can raise awareness of what we can offer for communication and make this appealing to residential aged-care facilities.

Theme 3: Speech pathologists have a desire to advance communication management in residential aged care

Of the 10 participants, eight commented that in "an ideal world" they would like to increase services for communication management in residential aged care. Most participants emphasised the importance of facilitating social communication among residents. Most participants also commented on the importance of ensuring that the individual communication needs of residents were assessed and that interventions provided were tailored to meet these needs. In doing so, participants acknowledged that all residents are not the same, "They might all have dementia but are still all very, very different" (Participant 3). All participants discussed several different roles that speech pathologists may take in facilitating resident communication. These roles included as consultants and doing "trouble shooting" (Participant 6) with both staff and residents when communication breakdown occurred, as educationalists providing training for residential aged-care staff and family members in maximising communication opportunity and success, and as clinicians providing both individual and group assessment and intervention services.

Discussion

With national and international aged-care legislation and reform recommendations emphasising the importance of person-centred care and therefore the maintenance of personhood (Productivity Commission, 2011; Department of Health, 2012; WHO, 2002), services to facilitate effective communication with clients are essential. In a setting such as residential aged care, where the majority of clients experience communication difficulty, there is marked potential for speech pathology services to facilitate

communication. In doing so, speech pathologists may further highlight the link between communication and participation, and between communication, subjective well-being, and person-centred care. In addition, the profile of this client group both within the speech pathology profession and in the wider health service and political arena may be raised.

Achieving service change for communication in residential aged care will, however, first require profession specific change. This Australian-based study supports prior international research (Hopper, Clearly, Oddson, Donnelly, & Elgar, 2007) indicating a degree of uncertainty and inconsistency among speech pathologists working in residential aged care. Key challenges include (a) inconsistency in perceptions about the importance and prioritisation of communication management in the setting and (b) uncertainty about the validity of assessment and intervention approaches with the client population, given the high prevalence of cognitive impairment and degenerative disease (Hopper et al., 2007). The current study also confirms the findings of previous studies indicating that the management of "swallowing" is the primary focus of speech pathology professional services in residential aged care (Bennett, Ward, Scarinci, & Waite, 2014; Casper, 2013; Hopper et al., 2007).

Further factors discussed that may inhibit speech pathology services for communication in residential aged care included resource constraints, lack of awareness of aged-care facility staff about communication management and the role of speech pathologists in providing this care, and limited education for speech pathologists specific to providing communication management in aged-care settings. These barriers are consistent with barriers identified as also inhibiting speech pathology management of mealtime difficulties in Australian residential aged care (Bennett et al., 2014). The impact of these barriers on both communication and mealtime management suggests the need for wider consideration of speech pathology service provision in residential aged care, including further exploration of the perceptions of a larger cohort of speech pathologists working in the setting. Such exploration may better guide training for speech pathologists working with older people and in residential aged-care settings, and may further assist in clarifying the current position of the profession in providing aged-care services.

Despite the challenges faced in working in residential aged-care settings, speech pathologists in the current study expressed a strong desire to expand communication management in the setting. To assist the majority of the resident population who experience communication difficulty as well as staff caring for these residents, and speech pathologists working in the setting, the profession must unite in advocating for the need for speech pathology services for communication in residential aged care. With current aged-care legislation and reform founded on the principles of person-centred care, there is current legislative support for communication management in the setting.

To assist speech pathologists entering the profession and clinicians already working in the setting, pre- and post-qualification training relevant to residential aged care must ensure clinicians are aware of challenges inherent in working in aged-care settings, and strategies to address these (Bennett et al., 2014; Hopper et al., 2007). Training in the management of cognitive-communication impairment and appropriate expectations for treatment outcomes must also be prioritised. This knowledge must

then be communicated to aged-care facility management and care staff, with speech pathologists taking the role of educationalist to raise awareness of opportunities to facilitate communication with residents with cognitive communication impairment. To achieve and sustain long-term change, current and future models of speech pathology service provision in residential aged care must be reviewed to better align with person-centred care. In doing so, the importance of effective communication in enabling meaningful life participation and facilitating subjective well-being must be highlighted.

Conclusion

As the population ages, the demand for speech pathology services in residential aged-care facilities will increase. As the majority of older people in residential aged-care facilities experience communication difficulty, greater attention is needed to determine how the speech pathology profession can optimise services to facilitate communication. Current speech pathology services targeting communication are limited and impacted by numerous barriers within and outside of the profession. The current data indicates that speech pathologists in this setting have a desire to increase the profile of communication management in residential aged care. Current aged-care legislation and reform is based on the principles of person-centred care and, thereby, provides a legislative platform on which to advocate for communication management in aged-care settings. As such, there is an opportunity for the profession to align itself with current aged-care legislation and reform, raise the profile of communication, and position the profession as a key player in the delivery of care to older people.

References

Ball, M. M., Whittington, F. J., Perkins, M. M., Patterson, V. L., Hollingsworth, C., King, S. V., & Combs, B. L. (2000). Quality of life in assisted living facilities: Viewpoints of residents. *Journal of Applied Gerontology*, 19(3), 304–325.

Bennett, M., Ward, E., Scarinci, N., & Waite, M. (2014). Perspectives on mealtime management in long-term aged care facilities in New South Wales, Australia: Insights from a cross disciplinary investigation. *Journal of Nutrition in Gerontology and Geriatrics*, *33*, 325–339.

Carpiac-Claver, M. L., & Levy-Storms, L. (2007). In a manner of speaking: Communication between nurse aides and older adults in long-term care settings. *Health Communication*, 22(1), 59–67.

Casper, M. L. (2013). Speech-language pathology in the long-term care setting: It isn't your Grandmother's nursing home anymore. Seminars in Speech and Language, 34(1), 29–36.

Department of Health. (2012). Living longer living better. Canberra: Department of Health, Australia.

Cruice, M., Worrall, L., Hickson, L., & Murison, R. (2003). Finding a focus for quality of life with aphasia: Social and emotional health, and psychological well-being. *Aphasiology*, *17*(4), 333–353.

Hilari, K., & Byng, S. (2009). Health-related quality of life in people with severe aphasia. *International Journal of Language & Communication Disorders*, 44(2), 193–205.

Hoffart, N. (1991). A member check procedure to enhance rigor in naturalistic research. *Western Journal of Nursing Research*, 13(4), 522–534.

Hopper, T., Cleary, S., Oddson, B., Donnelly, M. J., & Elgar, S. (2007). Service delivery for older Canadians with dementia: A survey of speech-language pathologists.

Canadian *Journal of Speech-Language Pathology and Audiology*, 31(3), 114–126.

Kitwood, T. M. (1997). *Dementia reconsidered: The person comes first*. Buckingham, UK: Open University Press.

Lubinski, R., & Welland, R. J. (1997). Normal aging and environmental effects on communication. *Seminars in Speech and Language*, *18*(2), 107–126.

Morgan, A., Hickson, L., & Worrall, L. (2002). The impact of hearing impairment on quality of life of older people. *Asia Pacific Journal of Speech, Language and Hearing*, 7(1), 39–53.

National Ageing Research Institute. (2006). *Personcentred health care*. Retrieved 21 June 2011 from http://www.nari.unimelb.edu.au/ochc

Nilsson, M., Ekman, S., Ericsson, K., & Winblad, B. (1996). Some characteristics of the quality of life in old age illustrated by means of Allardt's concept. *Scandinavian Journal of Caring Sciences*, *10*(2), 116–121.

Park, J. H., Yu, K. H., Lee, B. C., Kim, B. J., Bae, H. J., Lee, J... Kang, Y. (2013). Impact of post stroke cognitive impairment with no dementia on health related quality of life. *Journal of Stroke*, *15*(1), 49–56.

Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage Publications.

Pope, C., Ziebland, S., & Mays, N. 2000. Analysing qualitative data. *British Medical Journal*, 320(7), 114–116.

Productivity Commission. (2011). *Caring for older Australians*. Report No 53, Final Inquiry Report. Canberra: Productivity Commission.

Rabiee, F. (2004). Focus group interview and data analysis. *Proceedings of the Nutrition Society*, 63(4), 655–660.

Ritchie, J., & Spencer, L. (1994). Qualitative data analysis for applied policy research. In A. Bryman and R. G. Burgess (Eds.), *Analyzing qualitative data* (pp. 173–194). London, New York: Routledge.

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing and Health*, 23(4), 334–340.

Savundranayagam, M. Y. (2014). Missed opportunities for person-centered communication: Implications for

staff-resident interactions in long-term care. *International Psychogeriatrics*, *26*(4), 645–655.

The Speech Pathology Association of Australia Ltd. (n.d.). *Find a speech pathologist*. Retrieved 2 March 2011 from http://www.speechpathologyaustralia.org.au/index.php?option=com_content&view=article&id=616<emid=77

World Health Organization (WHO). (2002). Active ageing: A policy framework. A contribution of the World Health Organization to the Second United Nations World Assembly on Ageing, Madrid Spain, April. Retrieved 2 March 2011 from http://whqlibdoc.who.int/hq/2002/WHO_NMH_NPH 02.8.pdf

Worrall, L., Hickson, L., & Dodd, B. (1993). Screening for communication impairment in nursing homes and hostels. *Australian Journal of Human Communication disorders*, *21*(1), 53–64.

Yorkston, K. M., Bourgeois, M. S., & Baylor, C. R. (2010). Communication and aging. *Physical Medicine & Rehabilitation Clinics of North America*, *21*(2), 309–319.

Dr Michelle Bennett is a lecturer in speech pathology at the Australian Catholic University. At the time of manuscript preparation Michelle was completing her PhD at The University of Queensland. Professor Elizabeth Ward is a professor at the Centre for Functioning and Health Research (CFAHR) and Conjoint Professor at The University Of Queensland. Dr Nerina Scarinci is a senior lecturer in speech pathology at The University of Queensland. Dr Monique Waite is a research fellow and project manager in the School of Allied Health Sciences at Griffith University. At the time of manuscript preparation she was a research assistant at the Centre for Functioning and Health Research (CFAHR) and The University of Queensland.

Correspondence to:

Michelle Bennett

School of Health and Rehabilitations Sciences University of Queensland PO Box 51 Holland Park, Brisbane Qld, 4121 phone: 02 9739 2643 email: michelle.bennett@acu.edu.au



Speech pathology services following traumatic brain injury

The perspectives of health care consumers

Kathryn A. O'Leary, Alastair D. McRae, Anna M. Copley, and Naomi A. MacBean

The primary objective of this research was to document barriers and facilitators relating to access to, utilisation of, and satisfaction with **SLP** services following traumatic brain injury (TBI) across the continuum of care. The research consisted of semi-structured interviews with four adults with TBI and two significant others, analysed according to an interpretive phenomenology research methodology. Three key themes were identified: equity in service provision (availability and utilisation of services), management approach (collaborative goal-setting, alignment of intervention with goals, family involvement), and searching for information. Experiences with SLP services during rehabilitation were valued by individuals with TBI and their significant others. To further improve access to, utilisation of, and satisfaction with services, a person-centred approach to management with ongoing family involvement coupled with timely provision of accurate and appropriate information is suggested.

raumatic brain injury (TBI) is a major cause of morbidity and mortality worldwide (Perel, Edwards, Wentz, & Roberts, 2006), resulting in a multitude of cognitive communication, psychosocial, and physiological deficits; as diverse and heterogeneous as the adults and injuries themselves for those who survive (Johnson & Jacobson, 2007). Motor speech disorders (85%), dysphagia (42%), and cognitive communication disorders (CCD) (80-100%) are prevalent within this clinical population, having the potential for profound negative impact on quality of life and overall well-being (Degeneffe & Lee, 2010). Targeted speech pathology intervention, particularly if started early within the acute recovery stage, assists in achieving maximal rehabilitative outcomes; fostering increased confidence, independence, and return to employment (Togher, Power, Rietdijk, McDonald, & Tate, 2012). Following hospital discharge, however, access to health care services for individuals with TBI has been shown to decline progressively (Lefebvre, Pelchat, Swaine, Gelinas, & Levert, 2005; O'Callaghan, McAllister, & Wilson, 2010),

with negative implications for both the person with TBI and significant others (O'Callaghan, McAllister, & Wilson, 2011).

Adapting to the changes following TBI can be extremely difficult, not only for adults with TBI but also for their families. In the years following hospital discharge, most of the responsibility for supporting a person with TBI falls on the family or significant others (Bayen et al., 2014). The impact upon families providing this care is frequently underestimated (Wells, Dywan, & Dumas, 2005). Given the impairments sustained as a result of a person's TBI, relatives may be faced with the prospect of coping with a person who is very different from the one they knew before the trauma. The impact of this caring role on family life and relationships can be profound and often does not diminish with time (Knight, Devereux, & Godfrey, 1998). Common caregiver reactions include anxiety, shock, disbelief, denial, and frustration (Vogler, Klein & Bender, 2014). Consideration of the needs of those filling the carer role is essential, given that 80% of adults who survive TBI reintegrate into the community and require ongoing support and care from their families (O'Callaghan, et al., 2011).

As organisations and professions embrace contemporary recommendations for patient-centred approaches, individual perceptions of care following TBI are increasingly recognised, with particular emphasis on equity of access to, and utilisation of, health care services. Existing research suggests that individuals with TBI may experience inequity in accessing ongoing health care following discharge from hospital, with associated detrimental impact on health outcomes, particularly for those living in geographically isolated regions (Health Department of Victoria, 1991: Mitsch, Curtin, & Badge, 2014; O'Callaghan, McAllister, & Wilson, 2009). It is unclear if this inequity in general health care also applies to access to speech-language pathology (SLP) services, and whether or not other potential sources of inequity in the provision of TBI services (e.g. the provision of inadequate service, or limitations in access to SLP services due to eligibility criteria or referral practices) are perceived to be present by service users. Therefore, the objective of this study was to identify barriers and facilitators influencing access to, utilisation of, and satisfaction with SLP services, from acute care to community living, as experienced by participants with TBI (PWTBI) and their significant others (SO).

Method

An interpretive phenomenology research methodology was adopted to collect and analyse data to investigate participants' individual experiences of SLP services.

KEYWORDS

BEST PRACTICE
CONTINUUM OF

HEALTH CARE ACCESS

CARE

INTERPRETIVE PHENOMENOLOGY

PERCEPTION OF CARE

TRAUMATIC BRAIN INJURY (TBI)

THIS ARTICLE HAS BEEN PEER-REVIEWED



Kathryn A. O'Leary

Interpretive phenomenology is a research methodology that aims to analyse the significance of participant experiences and offer insight into their own interpretation and comprehension of these experiences (Tuohy, Cooney, Dowling, Murphy, & Sixsmith, 2013). This methodology allows the researcher to evaluate the data using qualitative analysis, while still preserving objectivity and rigour. This is achieved through a process known as "bracketing", whereby the everyday assumptions, attitudes, and prejudices of the researchers are put aside to focus on describing the participants' experiences of the phenomenon in its purest form (Tuohy et al., 2013). Interpretive phenomenology allows the participants' experiences to be classified under general themes and summarised with the use of key quotes that clarify each individual's experience (Ivey, 2013). The use of this coding system permits a level of insight into the key issues experienced by persons with a TBI and their significant others (SO) while accessing SLP services.

Participants

Two groups of participants were recruited for the project: (a) adults of working age (18–65 years) who sustained a severe TBI between 1998 and 2012 and who had accessed SLP services following injury and (b) their nominated significant other. An invitation to participate in the study was disseminated via the e-newsletter and Facebook page of Synapse (formally The Brain Injury Association of Queensland), a disability organisation for those living with acquired brain injury. The organisation is based in Queensland, but is able to be accessed nationwide, thereby providing reach to individuals throughout Australia. Purposive sampling was also used to assist in recruitment of individuals from states other than Queensland. This

approach (purposive sampling) allows researchers to recruit participants with particular characteristics which will allow them to answer the research questions (Guarte & Barrios, 2007).

Four male Australian residents with TBI, and two female significant others (wife and defacto partner) participated in the study. Three of the four men sustained a TBI through a motor vehicle accident, the other following a physical assault. Two of the male participants had returned to work following their TBI, however only one was employed in his previous capacity (see Table 1).

Data collection

PWTBI and their SOs completed online surveys (available on request) prior to attending an in-person interview with two researchers. The surveys were first piloted with speech pathologists with extensive clinical and research experience in the field of TBI, and further refined through the ethics application process. Participants were informed that assistance from a SO was permitted during survey completion to mitigate any potential difficulties experienced as a result of cognitive-communication or literacy impairments. Surveys were completed online through the web-based generator Survey Monkey.

Semi-structured interviews (30–45mins) were conducted, with one interview taking place at the University of Queensland campus and the remaining five via teleconference. These interviews aimed to qualitatively explore the continuum of care experienced by adults with a brain injury, employing a topic list to ensure coverage of all relevant areas. Interviews were audio recorded for later analysis. Ethical clearance for this study was granted by the University of Queensland's Behavioural and Social Sciences Ethical Review Committee.





Anna M. Copley (top), and Naomi A. MacBean. Alastair D. McRae photo not supplied

Table 1: Pa	Table 1: Participant details							
Pseudonym	Age	Gender	Time since injury	Location	Role	Employment status pre TBI	Employment status post TBI	Stage of recovery where SP was accessed
Gordon	26	Male	1 year	Vic	Person with a TBI	Employed	Employed	Intensive care, inpatient rehabilitation, outpatient rehabilitation
Thomas	42	Male	15 years	Vic	Person with a TBI	Employed	Unemployed – Studying	Live-in rehabilitation
Mitchell	33	Male	7 years	Qld	Person with a TBI	Employed	Employed at family firm	Intensive care, inpatient rehabilitation, live-in rehabilitation (biru), outpatient rehabilitation, ongoing rehabilitation
Mary	60	Female	2 years	Qld	Significant other	Employed	Retired	Outpatient rehabilitation, ongoing rehabilitation
Trevor	34	Male	1 year	Qld	Person with a TBI	Employed	Unemployed – on a disability pension	Inpatient rehabilitation, outpatient rehabilitation, ongoing rehabilitation
Samantha	27	Female	1 year	Qld	Significant other	Employed	Unemployed – on a disability pension	Inpatient rehabilitation, outpatient rehabilitation, ongoing rehabilitation
Note. Pseudor	ıyms hav	e been used	d to maximis	se participant	privacy and co	onfidentiality.		

Data analysis

Data collected from the interviews were first transcribed, then analysed using thematic analysis. This involved the identification, coding, and categorisation of emerging patterns in the data. Each transcript was analysed separately before all data were collated to examine recurring themes. To increase rigour, an expert in the field independently reviewed the themes identified during the coding process. The central ideas expressed by each interviewee were extracted and returned to the participant to ensure data interpretation was accurate. All participants agreed with the identified themes, and as such no changes were made as a result of this process.

The survey data were used to analyse the participants' experiences in relation to key aspects of their presentation, including age, gender, severity of injury (as reported by the participants), location, their role as a PWTBI or SO, employment status before and following TBI, and the stage of recovery at which SLP services were accessed.

Results and discussion

Three key themes were identified as descriptive of the perceived experience of SLP services following TBI: (a) equity in service provision, (b) management approach, and (c) searching for information.

Theme 1: Equity in service provision

Two key dimensions were identified as influencing equity of SLP service provision: (a) availability of services and (b) utilisation of services.

Dimension 1: Availability of services

All participants with TBI reported accessing SLP services within both acute and rehabilitation settings in the public health system, with three of the four also accessing public health outpatient SLP services. Three of the four PWTBI received additional services through private health insurance following hospital discharge. In contrast to previous literature findings of a decline in the quality and continuum of health care following discharge from hospital services (Lefebvre et al., 2005; O'Callaghan et al., 2010), participants in this study perceived greater ease of access to services during the later stages of recovery. The presence of a case manager (accessed by 4/6 participants) was identified as a major facilitator to accessing ongoing specialist care. "We've got a case worker so she was in contact with the insurance plus all the therapists and she gave us [the current speech pathologist's] phone number and she organised sessions with the speech therapist" (Samantha, SO).

Gaining access to frequent and regular therapy sessions was reported to be more difficult during inpatient and

Table 2. Themes and dimensions						
Theme 1	Equity in service provision					
Dimension 1 Dimension 2	Availability of services Utilisation of services					
Theme 2	Management approach					
Dimension 1 Dimension 2 Dimension 3	Collaborative goal-setting Alignment of intervention with goals Involvement of family members					
Theme 3	Searching for information					

early outpatient care. Samantha, Trevor's SO, reported wanting "more of speech, it should be provided frequently and constantly" and being left frustrated during a 6-week absence of SLP input during inpatient rehabilitation, "I don't know if she [speech pathologist] had too much to do or if she had too many clients, I don't know".

Changing service providers was also identified as a barrier to accessing services within the hospital setting:

We did butt heads. It was a difference in functional output as opposed to doing an assessment, getting objective data and then telling you you've got this this and this wrong. [But] it was harder to get another therapist because I did request. (Gordon, PWTBI)

Dimension 2: Utilisation of services

Key facilitators and barriers to utilisation of services were identified as being the availability of home visits following discharge to community living (generally privately funded) and knowledge of the role of the SLP in the rehabilitative process. While home visits facilitated utilisation of services, participants were generally unaware of the range of services offered by SLPs, resulting in inadequate coverage of their needs in some cases. Mitchell (PWTBI) stated "I was having a lot of trouble with breath control; when to take pauses, when to take breaths, facial expressions [and] body language, but I realised you guys [speech pathologists] don't do too much of that".

Participants reported that they would have preferred to receive more information regarding the scope of practice of SLPs, with specific details on the availability of services throughout the rehabilitation process. Absence of such information has been previously associated with detrimental impact on service utilisation, perceived support, and ultimate rehabilitative outcomes following TBI (Phillips, Greenspan, Stringer, Stroble, & Lehtonen, 2004).

Theme 2: Management approach

Three interrelated dimensions of this theme were extracted from the data: (a) collaborative goal setting, (b) alignment of interventions with goals, and (c) involving family as a fundamental member of the rehabilitation team.

Dimension 1: Collaborative goal-setting

Similar to existing literature reports, goals for rehabilitation were reported to be predominantly determined by the clinician (Leach, Cornwell, Fleming & Haines, 2010; O'Callaghan et al., 2010), particularly in the early stages of recovery. Participants reported dissatisfaction with, and disengagement from, the therapeutic process as a result.

I wanted to do all these things just around work and returning to work and she [SLP] was big on just making it more task related, just really focusing on what the assessments focused on... it wasn't really a compromise it was just dictated. (Gordon, PWTBI)

In contrast, when a person-centred therapy approach was adopted, as in previous investigations (DiLollo & Favreau, 2010), participants reported high levels of satisfaction, active engagement in setting and attaining goals, and perceived improved quality of care. As Mitchell reported, "the current speechie [SLP] I'm seeing at the moment, we undergo planning every six months or so. We have a review, or an update, or plan a new set of goals. She's very good". His recommendation to SLPs: "Individually assess your patients and actually work for them, work on their goals, don't just put them off to the side" Mitchell (PWTBI).

Dimension 2: Alignment of intervention with goals

While all participants remarked that they considered speech therapy to be a beneficial component of their rehabilitation and would recommend it to others in the future, not all participants were satisfied with the intervention approaches chosen by clinicians. In general, participants reported a preference for functional activities, clearly aligned with attaining relevant goals. "The most beneficial was doing a lot of the return to work therapy" (Gordon, PWTBI).

Flexibility in approach, appropriate choice of task difficulty, and speed of progression were reported to influence clinician–client relationships, and impact perception of overall standard of care.

I was put in front of a computer doing quizzes which were testing my vocabulary and recall which I didn't have too much trouble with. It was essentially a waste of time. I think the worst score I got was 8 out of 10 but usually 9 or 10 out of 10. That went on for months and months and I was like, what am I doing? It seemed pretty stupid to me. I've a feeling the speechie [SLP] didn't realise that I was actually a semi-intelligent sort of guy. (Mitchell, PWTBI)

Communication between members of the multidisciplinary team was also reported to influence participant experience. When reflecting on care received in the hospital system, Mitchell (PWTBI) stated: "I'm not sure they work together as such, it was kind of like Chinese whispers but I'm sure they had their way". A similar theme was reported by Gordon (PWTBI) who described his care as being "Very subdivided, you see a psychologist and then you see a speech pathologist and the speech pathologist didn't touch one ounce on the cognitive issues that I had".

Dimension 3: Involvement of family members

Involvement of family members in rehabilitation is known to positively impact quality of life, with support from significant others recognised to form a key environmental factor in the World Health Organisation's International Classification of Functioning - Disability and Health (WHO, 2011). Indeed, inclusive communication with the family or primary caregiver is considered essential when providing services to an individual with a TBI (Forster et al., 2012). However, in the course of this study, little evidence was found to show families had been included in rehabilitation by an SLP. This was perceived by participants as impeding quality of care, demonstrating little concern of the impact of TBI on the family, and inadequate recognition of their potential to assist in the recovery process. Mitchell (PWTBI) stated: "I'll say that they [Mitchell's family] came to one or two sessions over the course of a year as an outpatient. The hospital? No, not at all. Totally closed door". Similarly, Mary (SO) reported "My significant other and I were supposed to have a meeting in the hospital with the doctors and the speech pathologist and the physio [physiotherapist], but that never ever happened".

Theme 3: Searching for information

In line with previous research (O'Callaghan, McAllister, & Wilson. 2012), participants reported deficits in the amount, timing, and appropriateness of information provided by the health care team to have a negative impact on their perception of support and engagement in therapy. Lack of information of possible symptoms resulted in undue anxiety and distress in some cases, "My speech was ... the TBI had affected it. My talking sounds very different now.

That was a bit traumatic but I couldn't do anything about it anyway, so I just let it be" (Thomas, PWTBI), and in general PWTBI or their SO reported the need to actively seek out information on TBI, associated communication impairments, and available rehabilitative services independently, due to a perception that the information provided by the speech pathologist was insufficient, biased or confusing. To do so, they reported employing strategies of personal networks, the internet, or other professionals. As Mary reported: "I started googling, mainly because we couldn't get information, it was really hard getting information. We were in limbo as to how we proceeded" (Mary, SO).

When information was received participants reported feeling confused and overwhelmed by the content, relevance, and/or differing opinions of the professionals providing the information. As Mitchell describes:

There was a group run by the neuropsychologist and she was very good. But again, that was totally voluntary, no one actually forces you to listen to this, you work it out for yourself pretty much. It's sorting the chaff from the wheat. It's all very confusing for everyone involved. I mean, I didn't know anyone who had a brain injury and my family didn't either so we had no idea. All of my injuries or all of my problems we've discovered since and obviously some people in hospital have very set ideas on things. (Mitchell, PWTBI)

Future directions and clinical implications

This study highlights facilitators and barriers to optimum access and utilisation of SLP services for PWTBI in Australia. The small sample size is acknowledged, and data from this study should be interpreted as a preliminary investigation into the perceptions of SLP service users. In particular, it should be noted that all PWTBI included in this study were male, and SOs were female. Participants received services within two Australian states within the past 15 years. Given that much has changed in the field of rehabilitation during this time, a comparison of therapeutic approaches and practice guidelines across this period may be warranted. In addition, perceptions of service may differ for individuals in other states, of different gender, of varying severity levels, and those currently receiving SLP services within Australia.

The parallels between service user experiences and current recommendations for best practice are striking. Participants highlighted key aspects associated with perceptions of SLP services in concert with the literature, including equity in access and utilisation of services; use of a holistic, multidisciplinary, person-centred approach to management; and the benefits of providing individuals and their significant others with timely, accurate, non-biased, and appropriate information. Crucial to satisfaction and positive outcomes was a strong, collaborative clinician—client relationship. These findings warrant investigation on a larger scale, preferably of a prospective nature in order to capture current practice of SLPs within Australia, and how this relates to service users' perceptions of care.

Acknowledgements

This research received no specific grant from any funding agency, commercial or not-for-profit sectors.

Declaration of interest

None.

References

Bayen, E., Jourdan, C., Ghout, I., Darnoux, E., Azerad, S., Vallat-Azouvi, C., ...Azouvi, P. (2014). Objective and subjective burden of informal caregivers 4 years after a severe traumatic brain injury: Results from the PariS-TBI study. *Journal of Head Trauma Rehabilitation*, *51*, 163–184.

Degeneffe, C. E. & Lee, G. K. (2010). Quality of life after traumatic brain injury: Perspectives of adult siblings. *Journal of Rehabilitation*, 76(4), 27–36.

DiLollo, A., & Favreau, C. (2010). Person-centered care and speech language therapy. *Seminars in Speech and Language*, *31*(2), 90–97.

Forster, A. M., Armstrong, J., Buckley, A., Sherry, J., Young, T., Foliaki, S., ... McPherson, K. M. (2012). Encouraging family engagement in the rehabilitation process: A rehabilitation provider's development of support strategies for family members of people with traumatic brain injury. *Disability and Rehabilitation*, 34(22), 1855–1862.

Guarte, J. M., & Barrios, E. B. (2007). Estimation under purposive sampling. *Communications in Statistics – Simulation and Computation*, 35(2), 277–289.

Health Department of Victoria. (1991). Summary of report of "Head injury impact" project. Health Department Victoria, Community Services Victoria and Transport Accident Commission.

Ivey, J. (2013). Interpretive phenomenology. *Pediatric Nursing*, 39(1), 27.

Johnson, A. F., & Jacobson, B. H. (2007). *Medical speech language pathology: A practitioners guide* (2nd ed.). New York: Thieme Medical Publishers, Inc.

Knight, R. G., Devereux, R., & Godfrey, H. P. (1998). Caring for a family member with a traumatic brain injury. *Brain Injury*, *12*, 467-481.

Leach, E., Cornwell, P., Fleming, J., & Haines, T. (2010). Patient centered goal-setting in a subacute rehabilitation setting. *Disability & Rehabilitation*, 32(2), 159–172.

Lefebvre, H., Pelchat, D., Swaine, B., Gelinas, I., & Levert, M. J. (2005). The experiences of individuals with a traumatic brain injury, families, physicians and health professionals regarding care provided throughout the continuum. *Brain Injury*, *19*(8), 585–597.

Mitsch, V., Curtin, M., & Badge, H. (2014). The provision of brain injury rehabilitation services for people living in rural and remote New South Wales, Australia. *Brain Injury*, 28(12), 1504–1513.

O'Callaghan, A., McAllister, L., & Wilson, L. (2011). Experiences of care: Perspectives of carers of adults with traumatic brain injury. *International Journal of Speech-Language Pathology*, 13(3), 218–226.

O'Callaghan, A., McAllister, L., & Wilson, L. (2010). Experiences of care reported by adults with traumatic brain

injury. International Journal of Speech Language Pathology, 12(2), 107–123. doi:10.3109/17549500903431774

O'Callaghan, A., McAllister, L., & Wilson, L. (2009). Has quality of care for rural and non-compensable traumatic brain injury clients improved? *Australian Journal of Rural Health*, 17(3), 119–123.

O'Callaghan, A., McAllister, L., & Wilson, L. (2012). Insight vs readiness: Factors affecting engagement in therapy from the perspectives of adults with TBI and their significant others. *Brain Injury*, *26*(13–14), 1599–1610.

Perel, P., Edwards, P., Wentz, R., & Roberts, I. (2006). Systematic review of prognostic models in traumatic brain injury. *BMC Medical Informatics and Decision Making*, 6(1), 38–48

Phillips, V. L., Greenspan, A. I., Stringer, A. Y., Stroble, A. K., & Lehtonen, S. (2004). Severity of injury and service utilization following traumatic brain injury: the first 3 months. *Journal of Head Trauma Rehabilitation*, 19(3), 217–225.

Togher, L., Power, E., Rietdijk, R., McDonald, S., & Tate, R. (2012). An exploration of participant experience of a communication training program for people with traumatic brain injury and their communication partners. *Disability and Rehabilitation*, 34(18), 1562–1574.

Tuohy, D., Cooney, A., Dowling, M., Murphy, K., & Sixsmith, J. (2013). An overview of interpretive phenomenology as a research methodology. *Nurse researcher*, *20*(6), 17–20.

Vogler, J., Klein, A-M., & Bender, A. (2014). Long term health-related quality-of-life in patients with acquired brain injury and their caregivers. *Brain Injury*, 28(11), 1381–1388.

Wells, R., Dywan, J., & Dumas, J. (2005). Life satisfaction and distress in family caregivers as related to specific behavioural changes after traumatic brain injury. *Brain Injury*, 19(13), 1105–1115.

World Health Organisation (WHO). (2011). World report on disability. Retrieved from www.who.int/disabilities/world_report/2011/report.pdf

Kathryn O'Leary is a certified practicing speech pathologist currently working in private practice. Alastair McRae is a speech pathologist currently working in the United Kingdom. Dr Anna Copley is a speech pathology lecturer in the Division of Health and Rehabilitation Services at the University of Queensland. At the time of this investigation, Dr Naomi MacBean was a lecturer in speech pathology at the University of Queensland, Australia. Naomi is currently a clinical researcher at the University of Wisconsin-Madison, USA.

Correspondence to:

Anna M. Copley

Division of Speech Pathology School of Health & Rehabilitation Sciences The University of Queensland, St Lucia, Qld 4072 phone: +61 7 3365 6087 email: a.ocallaghan2@uq.edu.au



Volunteer-led aphasia groups in the community

Critical success factors in their sustainability

Anne Whitworth, Suze Leitão, Melanie Breese, Louise Cato, and Jade Cartwright

KEYWORDS

APHASIA
SUPPORT GROUP
COMMUNICATION
FRAMEWORK
COMMUNITY
COMMUNICATION

SUSTAINABILITY MODEL

> VOLUNTEER SKILLS

THIS ARTICLE
HAS BEEN
PEERREVIEWED





Anne Whitworth (top) and Suze Leitão

Community based volunteer-led communication groups for people with aphasia and chronic communication impairments following acquired brain injury may provide a much needed longer-term support system. Understanding what underlies the success of these community groups and the way in which they interface with speech-language pathology services is critical to developing a sustainable model for such groups. This study aimed to identify the critical factors contributing to the success of a long-running weekly volunteer-led communication group in Perth, Western Australia, that has had consistent monthly input by a speech-language pathologist. A qualitative study involving semi-structured interviews, analysed thematically, was conducted with four group members and four carers associated with the group to explore factors relevant to its success. From the 14 themes that emerged, six critical internal factors and three critical external factors emerged to inform a model of sustainability.

he impact of communication impairments arising from aphasia and other sequelae of acquired brain injury on the individual is well documented, with reduction in social interaction and role changes commonly resulting in psychological and emotional problems persisting beyond the period of therapeutic intervention (Cruice, Worrall & Hickson, 2006; Kauhanen et al., 2000; Sarno, 1993). The complex set of barriers to successfully achieving a good quality of life for people living with longterm communication impairment is equally acknowledged, especially those related to adjustment (Mumby & Whitworth, 2012, 2013), and includes both internal emotional factors and more external societal and attitudinal factors. With speech pathology services limited in the post-acute phase and people frequently discharged from hospital into the community with little or no support, communication and aphasia support groups within the community have evolved as a vital forum for ongoing support for people with chronic communication impairment, including aphasia (Code &

Petheram, 2011; Elman & Bernstein-Ellis, 1999; Hersh. 2008). Such community-based groups act to provide stimulation, social support, conversational opportunities and a sense of belonging (e.g., Hersh, 2006; Legg, Stott, Ellis, & Sellers, 2007; Simmons-Mackie & Elman, 2011). Within a social model of aphasia intervention, the physical environment of the group setting has provided opportunities for both 'functional communication', i.e., successful relaying of the message over linguistic accuracy, and 'total communication', where any or all means and modalities of communication are encouraged to send or receive a message, in a relatively naturalistic context (Byng, Pound, & Parr, 2000; Lawson & Fawcus, 1999; Lyon, 1996). A supportive atmosphere for communication of emotions and reactions with regard to the stroke or traumatic brain injury is also provided, with the potential for members to develop emotional and psychological bonds that help them cope with the consequences of having aphasia (Kearns & Elman, 2001; Mumby & Whitworth, 2013). Practising new communication strategies in safe group environments forms part of the adjustment process in living with communication impairment, while providing the opportunity to develop and reinforce internal coping strategies. In addition, a recent systematic review of 29 studies (Lanyon, Rose, & Worrall, 2013) relating to both outpatient and community groups reported improved language processes amongst participants, although it found less conclusive evidence with respect to functional communication.

That community communication groups can assist in overcoming the barriers encountered by people with communication impairments is not disputed here – their organisation and viability in a pressured health care system, however, is a challenge. In a recent survey of aphasia rehabilitation practices of 188 speech pathologists in Australia, 44% of clinicians reported minimal or no follow-up of adults once they were discharged from community and out-patient services (Rose, Ferguson, Power, Togher, & Worrall, 2014), highlighting the need for solutions to be identified that might address the long-term needs of these populations.

Developing a local model

Within the context of the high demand on health services, Communicate WA (formerly Reconnect WA), a user organisation for people with communication impairments, was formed in Perth, WA, in 2006. Communicate WA aims to provide services and advocacy for those living with acquired communication impairments, in particular aphasia, and usually after public services are no longer available. As

Table 1. Characteristics of participants with communication impairment and carers									
Participants with communication impairment Carers									
Participant	1	2	3	4	1	2	3	4	
Age	63	75	67	45	48	50	53	65	
Gender	М	M	F	F	М	М	F	F	
Diagnosis	Mild aphasia	Mild aphasia	Mod/sev aphasia	Ataxic dysarthria					
Years post onset	18	29	2 ½	27					
Time (months) involved with group	10	4	1	5	3	12	1	5	

a volunteer-led charity, the organisation oversaw, at the time of the study, two community conversation-based groups (identified here as group 1 and group 2) in metropolitan Perth, led either by volunteers or by members with communication impairment. Of these groups, only group one had been considered successful as evidenced by its continual recruitment, and attendance of regular members, over nearly a 13-year period; 82 people had attended the group during this time (attendance averaged two to three years, ranging from one session to 12 years) while group 2 faced dissolution at the time of the study. Both groups were volunteer led and had been set up with initial funding by the Rotary Health Foundation. One difference lay, however, in the regular, low-intensity speech-language pathology (SLP) involvement that had been maintained in group 1 and not the other. The SLP involvement was in a voluntary capacity, eventually coming under the umbrella of Communicate WA. With the charity exploring the viability of setting up further groups throughout the same geographical region, a model which suited local conditions was needed and an analysis of the critical success factors was undertaken to explore which specific factors underpinned the success of the group and, in particular, the extent to which SLP involvement was regarded as critical. The group, known as the Fremantle Communication Group, has met weekly since its inception with the SLP attending monthly throughout this period. The role of the SLP focused on volunteer training, along with active promotion of established communication frameworks, e.g., Supported conversation for adults with aphasia (SCA; Kagan, 1998) where volunteers are trained in communicative strategies and have appropriate materials available to support this, and "total communication" where all communication methods are facilitated. Additionally, the SLP provided information on the communicative skill level of each new member in liaison with local health services.

Aims of the study

This study aimed to examine the communication group experiences of group participants and their carers to identify which factors have contributed to the success and longevity of the Fremantle Communication Group. This process sought to facilitate reflection on how these factors might generalise to other contexts/groups with the view to informing a sustainable model for further communication groups. Integral to this aim was the need to isolate the contribution of the professional support, identifying to what extent this was critical and, if so, which components.

Method

Ethics approval was received from the Human Research Ethics Committee at Curtin University (SPSP 2011/49).

Participants

All group participants, carers and volunteers associated with the Fremantle Communication Group were invited to participate in the study. Four group participants and four family carers of participants from the Fremantle Communication Group (unrelated to each other) gave written consent to participate in the study using plain English and/or aphasia-friendly materials. Participants were aged between 45 and 75 years with a range of diagnoses following brain injury, mainly stroke (see Table 1). Three participants had mild to moderate aphasia while the fourth participant had a moderate ataxic dysarthria. They had attended the group for between 1 and 10 years. The carers interviewed were aged between 48 and 65 years and had been associated with the group for between 1 and 12 years. Carers did not attend the weekly group but were included in order to explore their experiences of the participants' attendance at the group.

Procedure

All participants completed a semi-structured interview conducted in their own homes or at a suitable location selected by them. The interview involved a series of topics relating to their involvement in the group, such as (a) their motivation for attendance or their family member's attendance; (b) how the group functions, in particular, in relation to the volunteers; and (c) the impact of the group on their own and their family members' lives. The participants were not directly asked to provide their view on what they thought contributed to the success of the group or to assess the influence of the speech pathologist's involvement. These topic areas provided a guide for the interviewer whereby the interviewer could stray from the protocol or delve further into particular issues when deemed appropriate. Each interview was between 30 and 45 minutes, using principles set out by Luck and Rose (2007) for interviewing people with aphasia, and framed by supported conversation techniques (Kagan, 1998). The interviews were conducted by a SLP student who was provided with training through practice interviews and feedback, and recorded digitally and transcribed verbatim and orthographically by the interviewer (Onwuegbuzie & Leech, 2007). Members of the research team checked 10% of the interview data for transcription accuracy against the audio-files to ensure the transcriptions were an accurate record of the discussion.

Data analysis

Thematic analysis is an approach used to recognize and report themes within a data set (Braun & Clarke, 2006). Using NVivo9, the process for this study followed the







Melanie Breese (top), Louise Cato (centre) and Jade Cartwright

guidelines set by Braun and Clarke (2006), working through the stages of gaining familiarity with the data, generating initial codes, and identifying, defining and then reviewing themes. Initial analysis was conducted by one author, with data and themes reviewed and agreed upon by three further members of the research team. Review was carried out at different stages until no new themes could be identified in the available data. Data from the participants with aphasia and carers was coded separately to identify themes relevant to each group. Further discussion then took place among team members to identify whether broader themes emerged from the data. The broader themes that emerged were then related back to the study aims (as per phase 6, Braun & Clarke, 2006), to consider whether these themes cohered around factors that would facilitate the development of a sustainable model for volunteer-led groups.

Results

Fourteen themes were identified in the data from the group members and carers, as presented in Table 2. Nine themes were common to both groups, discussed here together, and included 1) the *skills of the volunteers* (including attributes, tasks undertaken and their ability to perform these); 2) acceptance of communication and the resulting ease of communication (including increased attempts to communicate and perceived improvement in production); 3) exposure to and support of those with *similar difficulties* (included not feeling embarrassed and feeling connected to others); 4) practice and improvement in talking (both in relation to weekly opportunities but also through the practice in repeatedly sharing their story with new group members); 5) enjoyment (expressed simply as being happily

engaged by the group); 6) social interaction and/or belonging (also discussed as friendship by the group participants); 7) the positive impact on carers and/or friends (including increased relaxation and ease created by the knowledge that the family member was engaged, and having the separate time); 8) the increased confidence gained by the participants; and, finally, 9) the routine and regularity of the group (in relation to regular weekly attendance). This final common theme was raised widely by the carers but only by one aphasia group member. In their reflections, three participants with communication impairments reported improved speech and/or language skills, captured across several of the above themes. An additional five themes were identified in the data. Group participants identified 10) the opportunity to help and learn from others (assisting others emerged as crucial for some members) and 11) to be understood (in contrast to feeling 'accommodated'). Carers additionally identified themes related to 12) the vulnerability of the group (particularly in the event of volunteer turnover); 13) and the small size of the group (this was approximately 6-8 at any one time, a factor that was viewed by carers as positive for group members); along with 14) the logistics of transport (transport was provided, where needed, a factor that was regarded highly). The additional themes raised by the carers related, on the whole, to practical issues around the group and an awareness of the need to maintain conditions in order for the group to be sustainable.

These fourteen themes characterised the communication group experiences of the group participants and their carers, suggesting a range of perceived benefits and positive outcomes. The themes were then further examined by the research team to identify six broader themes, each

Themes identified by group participants $(n = 4)$	No. of sources (max. 4)	No. of references	Themes identified by carers $(n = 4)$	No. of sources (max. 4)	No. of references			
Common themes								
Volunteer tasks and skills	4	29	Volunteers skills	4	13			
Acceptance and ease of communication	3	20	Acceptance and ease of communication	3	17			
Similar difficulties of others	4	17	Similar difficulties of others	4	10			
Practice and improving speech	3	10	Practicing and improving speech	2	5			
Enjoyment	4	9	Enjoyment	2	6			
Friendship and social belonging	1	4	Social interaction	4	8			
Positive impact on carers and friends	2	5	Positive impact on carer	4	6			
Confidence	1	3	Confidence	3	9			
Routine and structure	1		Regularity	3	6			
Different themes								
Helping and learning from others	2	5	Small size	1	2			
Being understood by others	2	5	Transport	2	4			
		2	Group vulnerability	1	2			

considered critical to the group's success and which included:

- 1. Volunteer skills. The first coalescence of factors revolved around the knowledge, skills, and personal attributes of the volunteer facilitators and was viewed as critical to the group's success, with listening skills rated highly, along with targeted facilitation of communication among people with a range of speech and language impairments. Having the highest number of references in the interviews, the importance of the volunteers in supporting the group success emerged strongly, playing an important role in facilitating a safe group environment and effective communication support and practice. The personal characteristics of demonstrating enthusiasm, empathy, confidence, and interest in group members were considered critical in the context of the unique contribution brought by each.
- 2. Communication opportunity. The second critical success factor around which several themes revolved was the opportunity to be engaged in communication, i.e., to be understood, to have time given to communicate, and to be supported in practising communication skills. One participant reported,

What it does is gives you confidence to talk among other people and to range your thoughts because if you have a brain injury or a stroke your brain is a bit scr- scrambled and see you need a chance to exercise that the way of thinking and to talk. (Participant 1)

Equally, the opportunity for social connection and

interaction was viewed highly, as was the opportunity

to both assist others and take the opportunity to learn from other group members, in particular with regards to strategies. Importantly, three of the four participants with communication difficulties reported increased speech and language skills – which was not the explicit intention of the group – contributing to their motivation to attend.

3. Communication framework. The value of a clear communication framework that informs the philosophy or culture of a communication group drew together a number of themes. Based around the total communication approach, themes relating to acceptance of communication, opportunity for safe and supported practice to improve speech, opportunity to help and learn from others, to be understood by others, and to experience

a sense of belonging were identified as key components of a successful communication framework or group culture.

Together these factors contributed to increased ease of

communication and overall confidence.

- 4. Group organisation. Themes relating to the routine and structure of the group, regularity of meetings, organisation of the facilities, logistics, such as transport and afternoon tea, group schedules, weekly preparation, and activities coalesced, indicating that effective group organisation was another factor critical to the success of the group. While the volunteers contributed to the smooth running of the weekly groups, the further organisation put in place by the SLP around meeting space, transport, and interaction with other service providers was acknowledged.
- 5. Environment. Several themes coalesced around the provision of a safe physical and supported social environment with this viewed as critical to the success of the group. With clear overlap between other areas (e.g., involving acceptance, belonging, being understood by others, similar difficulties of others), the environment was viewed as one where people understood, were accepting without judgment and where it was safe to make mistakes,

enabling opportunity to learn from others and facilitate a sense of purpose.

6. Shared experience. Each of the above five factors revolved around the final and, arguably, the central factor, that of the shared experience provided by the group. This was reflected in such comments as, "I'm getting the benefit of them struggling as I struggle" (Participant 3) and "Our group is friendly and we feel like we belong, a part of the group" (Participant 1). This experience is broadened here to include friendship, enjoyment, and a sense of group belonging.

Discussion

This study sought to examine the communication group experiences of group participants and their carers to identify which factors contributed to the success and longevity of a highly successful long-running community communication group for people with acquired brain injury (mainly stroke). It was anticipated that information drawn from the perspectives of a sample of both group participants and carers would allow the creation of a preliminary model for sustainable communication groups that could be implemented with future groups and be evaluated, and subsequently inform providers. Given a key difference between the successful group and the group facing dissolution in the same geographical vicinity was the involvement of an SLP, we were interested in the extent to which this influenced the group's success or whether the shared experience of the group may be sufficient to maintain the group as a viable entity.

While 14 themes were initially identified in the data set, further reflection of the data highlighted 6 broader themes which emerged from the data. These were considered, by their nature, to be critical *internal* factors as they related to the operation of the group. Underpinning these internal factors, however, were a series of critical *external* sustaining factors which involved organisational processes. Each of these factors are represented schematically in Figure 1 in a proposed model of communication group sustainability and discussed below.

Critical internal factors

The first internal factor, the skills of the volunteers, was acknowledged by the participants as fundamental to the

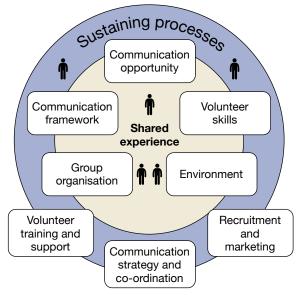


Figure 1. Model of communication group sustainability

gains in communication they experienced and their positive attitude towards attendance. Communication opportunity was the second factor and is represented consistently in the literature as provided by such groups, and relates to the opportunity to practice communication and interact socially in a safe, supportive, and accepting environment (Davis & Wilcox, 1985; Elman & Bernstein-Ellis, 1999; Lawson & Fawcus, 1999; Lyon, 1996; Rose & Attard, in press; Sarno, 1991). These two factors, the volunteers' skills and the communication opportunity, were underpinned by the third factor, suggesting the importance of a communication framework or group culture that mediates safe and supported opportunities for communication and social connection. In this case, the communication group was shaped by a theoretically motivated model for facilitating communication based on Kagan and colleagues' work on Supported conversation for adults with aphasia (1998). Used internationally in training and working with volunteers to support the communication of people with aphasia, this model aims to unmask the competence of people with aphasia, utilising whatever communication channels are available to them to facilitate effective communication. The models of communication were considered to explicitly inform interaction within the group, helping participants improve confidence and communication skill within an enjoyable, safe, and social context. Logistical factors related to group organisation and the environment involved roles primarily undertaken, in this instance, by the SLP involved in the group, encompassing both the physical environment and the scaffolded language environment. While the data from this study focused to a greater extent on social space rather than being the physical, the location of the space within the community, rather than being hospital based, supports work by Hersh (1998) as potentially also contributing to the ongoing success of the group. The final internal factor of shared experience, again, reinforces earlier work in the literature as to the value of groups and peer support for people with communication impairement in facilitating adjustment and positive coping (Mumby & Whitworth, 2012).

Critical external factors

In addition to the internal factors, three critical external factors were identified. These factors were not as transparent in the views reported by the participants in the study, but were regarded as essential and enabling of the internal factors. They were also particularly important as they highlighted the vulnerability of the group while drawing together issues related to the SLP involvement, each regarded as critical to the long-term success of the group. The three external factors, each of which were grounded in the data, covered a range of issues related to 1) ongoing recruitment, training, and support for volunteers to ensure adequate skill level and continuity; 2) strategic direction, group co-ordination, and logistics (such as transport and space); and 3) the marketing of the group and ongoing member recruitment. Sustainability, while not directly questioned of the participants, was an ongoing concern for all involved in the group.

1. Volunteers (training and ongoing support). While the importance of a communication framework was identified as a critical internal factor, the training of and ongoing support to the volunteers to understand and facilitate the framework to ensure a supportive communication group environment was seen as a critical factor external to the group. The modification of both the language and physical environments by the volunteers enabled communication to take place more easily and to be less effortful.

- 2. Strategic direction, group co-ordination, and logistics. Leadership, co-ordination, space, and transport issues were peripheral to why participants expressed they liked coming to the group but identified as critical to enabling them to attend. Carers, in particular, highlighted these issues along with their awareness of the importance of these to sustainability.
- 3. Recruitment (of members and volunteers) and group marketing. The ongoing liaison required to recruit members and volunteers to, and market, the group within the broader health service underpinned many of the themes that were raised, capturing several of the issues around the vulnerability of the group.

An overarching theme underpinning these external factors was the involvement of the SLP with relevant knowledge and experience in communication and facilitation of group behaviour. The SLP provided, monitored, and reinforced the model of supported communication that provided the foundation for communication between the volunteers and the group members, enabling effective communication to be practised, and provided ongoing training and monitoring of volunteer skills. While attending the weekly group only on a monthly basis, the SLP oversaw the recruitment, screening, and monitoring of members with communication difficulties, identifying communication needs of people within the health service and liaising with the other health professionals. The extent to which some of the logistical skills could be devolved to volunteers, and whether a monthly schedule is the ideal frequency for SLP involvement were both factors that were not addressed in this study. These questions could be addressed in future studies, particularly with respect to the second where different levels of SLP involvement could be compared. Identifying roles prepared to be undertaken by volunteers is also likely to be addressed through inclusion of volunteers in future studies.

The internal components of the model proposed here are supported by research in existing studies of aphasia group processes (Davidson & Worrall, 2013; Hoen, Thelander, & Worsley, 1997). Brown, Worrall, Davidson, and Howe (2010) identified four core themes relating to "living successfully with aphasia". These were doing things, having meaningful relationships, striving for a positive way of life, and communicating. Legg et al. (2007) undertook a similar study by interviewing members of community conversational groups run by volunteers in Scotland. The focus group identified both overlapping and similar themes of inclusion, interpersonal relationships, support, personal growth, and development, including learning, purpose, structure and routine, social identity, performance and productivity, and opportunities to influence others and be influenced. Hoen et al. (1997) demonstrated improvement in quality of life of attendees in a Canadian study. Similarly, a study by Vickers (2010) provided quantitative data about social networks before and after aphasia, and confirmed that attendance at a communication group increased social participation and a sense of social connectedness.

While each of these studies has highlighted the role of psychosocial factors in communication groups, this study of Fremantle Communication Group has also highlighted the critical role of the volunteers' skills, the importance of the communication environment, and the logistical processes that enable the sustainability of such groups. Although the factors related to shared experience were critical, these were unlikely to sustain the group without the professional

support provided to the volunteers and the communication strategy and co-ordination that underpinned the group. SLP expertise is therefore seen as crucial to a sustainable model for communication groups in the community. This outcome is not unexpected; however, access to SLP services by such groups does remain contentious. While the SLP in this study predominantly worked in a voluntary capacity, training provision by a volunteer SLP is not a sustainable option in the long-term. Strategic planning at a local level is clearly needed to ensure regular and ongoing input, albeit potentially not needing to be provided in the intensity that we might usually consider for our services. Strategies might include collaborative partnerships with universities or referring health services, allowing volunteer training to be delivered as part of final-year clinical placements or outpatient service delivery. The potential rotation or sharing of training across services (e.g., "releasing" staff to deliver training) could offer inexpensive but critical input that would ensure that outpatient services have somewhere to refer their clients after therapy ceases while addressing those long-term needs of people who have communication impairment.

This study has sought to explore the experiences of a particular community-based communication group in a particular locality. As such, it is confined to a small number of participants, influenced by the local conditions of the group involved. Future research should build on the current findings.

Conclusion

This study sought to identify which factors were perceived by group participants and carers to contribute to the success of a long-running volunteer-led communication group and explore the interaction between these factors. The provision of communication opportunities in a supported and rich communication environment with well-trained volunteers and robust organisation were viewed as critical to the day-to-day success of the group. The ongoing development of volunteer skills, the managed communication environment and the professional support with recruitment and strategic direction provided by the SLP in a regular but low-intensity model were found to underpin this success. This contributed to a proposed model of sustainability factors that should be explored further to assess its utility in informing the development of further community communication groups. Future studies should also explore the perspectives of SLPs and other relevant health professionals to establish the validity and utility of this preliminary model.

Acknowledgements

The authors wish to acknowledge the group and carer participants who took part in this study and Tess Beattie, Curtin University, who conducted the interviews as part of a School of Psychology and Speech Pathology, Curtin University Summer Scholarship. The study was funded through a small grant from the School of Psychology and Speech Pathology, Curtin University.

References

Braun, V., & Clarke V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101.

Brown, K., Worrall, L., Davidson, B., & Howe, T. (2010). Snapshots of success: An insider perspective on living successfully with aphasia. *Aphasiology*, 24(10), 1267–1295.

Byng, S., Pound, C., & Parr, S. (2000). Living with aphasia: A framework for interventions. In I. Papathanasiou (Ed.), *Acquired neurogenic communication disorders: A clinical perspective* (pp. 49–75). London: Whurr Publishers.

Code, C., & Petheram, B. (2011). Delivering for aphasia. *International Journal of Speech-Language Pathology*, 13(1), 3–10.

Cruice, M., Worrall, L., &, Hickson, L. (2006). Quantifying aphasic people's social lives in the context of non aphasic peers. *Aphasiology*, *20*(12), 1210–1225.

Davidson, B., & Worrall, L. (2013). Living with aphasia: A client-centred approach. In I. Papathanasiou, P. Coppens & C. Potagas (Eds.), *Aphasia and related neurogenic communication disorders* (pp. 255–271). Burlington, MA: Jones & Bartlett Publishers.

Davis, G., & Wilcox, M. (1985). *Adult aphasia* rehabilitation: *Applied pragmatics*. San Diego, CA: College Hill Press

Elman, R. J., & Bernstein-Ellis, E. (1999). The efficacy of group communication treatment in adults with chronic aphasia. *Journal of Speech, Language, and Hearing Research*, 42(2), 411–419.

Hersh, D. (1998). Beyond the "plateau": discharge dilemmas in chronic aphasia. *Aphasiology*, 12, 207–218.

Hersh, D. (2006). "From the ground up": The Talkback Group Program in South Australia. In R. J. Elman (Ed.), Group treatment of neurogenic communication disorders: The expert clinician's approach (2nd ed.), pp. 255–268. San Diego, CA: Plural Publishing Inc.

Hersh, D. (2008). How do people with aphasia view their discharge from therapy? *Aphasiology*, 23(3), 331–350.

Hoen, B., Thelander, M., & Worsley, J. (1997). Improvement in psychological well-being of people with aphasia and their families: Evaluation of a community based group. *Aphasiology*, *11*(7), 681–691.

Kagan, A. (1998). Supported conversation for adults with aphasia: Methods and resources for training conversation partners. *Aphasiology*, *12*(9), 816–830.

Kauhanen, M. L., Korpelainen, J. T., Hiltunen, P., Määttä, R., Mononen, H., Brusin, E., ... & Myllylä, V. V. (2000). Aphasia, depression, and non-verbal cognitive impairment in ischaemic stroke. *Cerebrovascular Diseases*, *10*(6), 455–461.

Kearns, K., & Elman, R. (2001). Group therapy for aphasia: Theoretical and practical considerations. In R. Chapey (Ed.), *Language intervention strategies in aphasia and related neurogenic communication disorders* (4th ed.; pp. 316–337). Baltimore, MD: Lippincott Williams & Wilkins.

Lanyon, L. E., Rose, M. L., & Worrall, L. (2013). The efficacy of outpatient and community based aphasia group interventions: A systematic review. *International Journal of Speech-Language Pathology*, *15*(4), 359–374.

Lawson, R., & Fawcus, M. (1999). Increasing effective communication using a total communication approach. In S. Byng, K. Swinburn, &C. Pound (Eds.), *The aphasia therapy file* (pp. 61-74). Hove, UK: Psychology Press.

Legg, L., Stott, D., Ellis, G., & Sellars, C. (2007). Volunteer stroke service (VSS) groups for patients with communication difficulties after stroke: A qualitative analysis of the value of groups to their users. *Clinical Rehabilitation*, 21(9), 794–804.

Luck, A., & Rose, M. (2007). Interviewing people with aphasia: Insights into methods adjustments from a pilot study. *Aphasiology*, *21*(2), 208–224.

Lyon, J. (1996). Optimising communication and participation on life for aphasic adults and their prime

caregivers in natural settings: A model for treatment. In G. Wallace (Ed.), *Adult aphasia rehabilitation* (pp. 137–160). Newton, MA: Butterworth Heinemann.

Mumby, K., & Whitworth, A. (2012). Evaluating the effectiveness of intervention in longterm aphasia post-stroke: The experience from CHANT (Communication Hub for Aphasia in North Tyneside). *International Journal of Language & Communication Disorders*, 47(4), 398–412.

Mumby, K., & Whitworth, A. (2013). Adjustment processes in chronic aphasia after stroke: Exploring multiple perspectives in the context of a community-based intervention. *Aphasiology*, *27*(4), 462–489.

Onwuegbuzie, A. J., & Leech, N. L. (2007). Validity and qualitative research: An oxymoron? *Quality & Quantity*, 41(2), 233–249.

Rose, M., & Attard, M. (In press). Practices and challenges in community aphasia groups in Australia: Results of a national survey. *International Journal of Speech Language Pathology*.

Rose, M., Ferguson, A., Power, E., Togher, L., & Worrall, L. (2104). Aphasia rehabilitation in Australia: current practices, challenges and future directions. *International Journal of Speech-Language Pathology*, *16*(2), 169–180.

Sarno, M. (1991). The psychological and social sequelae of aphasia. In M. Sarno (Ed.), *Aquired aphasia* (2nd ed.; pp. 499–519). San Diego, CA: Academic Press.

Sarno, M. (1993). Aphasia rehabilitation: Psychosocial and ethical considerations. *Aphasiology*, 7(4), 321–334.

Simmons-Mackie, N., & Elman, R. J. (2011). Negotiation of identity in group therapy for aphasia: The Aphasia Café. *International Journal of Language & Communication Disorders*, 46(3), 312–323.

Vickers, C. P. (2010). Social networks after the onset of aphasia: The impact of aphasia group attendance. *Aphasiology*, 24(6–8), 902–913.

Anne Whitworth is Associate Professor and Suze Leitão is Senior Lecturer in the School of Psychology and Speech Pathology, Curtin University, WA. Melanie Breese is Senior Speech Pathologist with Older Adult Mental Health, North Metropolitan Health Service, WA, and Communicate WA. Louise Cato is Clinical Lead with Amity Health, WA, and Communicate WA. Jade Cartwright was a lecturer at the Curtin University at the time of the study, and is now Lecturer at the University of Melbourne.

Correspondence to:

Dr Anne Whitworth

School of Psychology and Speech Pathology Department Faculty of Health Sciences Curtin University

Tel: +61 8 9266 3498

Email: anne.whitworth@curtin.edu.au



The future of speech pathology in aged care

Students' confidence and interest in working with older people

Ronelle Hewetson, Petrea Cornwell, Susannah Davern, Anne E. Hill, and Lucy Hunter

Australia's demographic future and need for allied health staff equipped to provide services to growing numbers of older people with complex care needs have been documented. Student interest in working with older people has been explored in a number of health care professions, but not in the field of speech pathology. This study investigated speech pathology students' attitudes toward older people; knowledge and confidence in clinical skills related to communication and swallowing disorders in older people; as well as interest in future employment that specialises in service provision to older people. Seventy-four participants completed an on-line survey and a geriatric attitude scale prior to a clinical placement in an adult service, with 52 completing a post-placement survey. Results indicated that students had positive attitudes about older people and that a clinical placement in an adult service increased their knowledge and confidence in clinical skills. Despite positive attitudes about older people, a preference for working with younger adults emerged. Implications for future training of speech pathologists are discussed and the need identified for research into factors that influence career interest.

ealth care provision to growing numbers of older Australians, those aged 65 and older, has been described as one of the most important medical and economic challenges facing Australia (Productivity Commission, 2013). Health expenditure for older people, who comprised 14% of the population in 2012, has reached four times what is required for those younger than 65 (Australian Institute of Health and Welfare [AlHW], 2012). People aged over 85 years, who are considered the major users of health care and aged-care services, comprise the greatest population growth demographic (AlHW, 2012). Not only are the numbers of older people requiring residential, hospital-based, and in-home services

increasing, there is also a reported increase in the levels of medical complexity and frailty of older people (AIHW, 2012). With advancing age, a higher incidence of chronic diseases and complexities associated with medical comprbidities emerges. In particular, the increasing prevalence of dementia, the greatest cause of disability for Australians over 65 years, will increase demand for complex care services (AIHW, 2012).

Australia's growing number of older people has been identified as an important consideration in recruitment of the future health workforce (Speech Pathology Australia [SPA], 2005) to ensure availability of allied health staff with the interest and skills to management of the needs of an older and more medically complex population. Speech pathologists will require specific skills to manage the communication and swallowing issues associated with this population, who will likely form a large proportion of clinical caseloads. Up to 95% of older people experience change in their communication ability that occurs as part of the normal ageing process or as a result of acute and chronic conditions (e.g., stroke, Parkinson's disease, adult acquired hearing impairment) with the potential to reduce communication-based activities and negatively affect quality of life (American Speech-Language-Hearing Association (ASHA), 1988; Kiely & Simon, 2000). Furthermore, service provision to adults with cognitive-communication disorders secondary to dementia has for several years been identified as a fast-growing clinical area for speech pathologists (SPA, 2012). Dysphagia management is another key area, with up to 55% of hospitalised people over 70 years (Cabre, Serra-Prat, Palomera, Almirall, & Pallares, 2010), 60% of people in residential care facilities, and 84% of people with dementia (Horner, Alberts, Dawson, & Cook, 1994) experiencing swallowing problems that can lead to compromised health and nutritional status (Lin, Wu, Chen, Wang, & Chen, 2002).

To ensure appropriate and sufficient service provision for older people across a range of contexts, speech pathology students require clinical placements that will help them to develop confidence and interest in working with this population. Previous research suggests a trend of students in medical and other allied health disciplines viewing work with older people as less desirable (Burg, Waddell, Doty, Horne, Weilgas, & Davidson, 2001; Courtney, Tong & Walsh, 2000) than other population groups. Studies examining possible reasons for this trend found that gaining theoretical knowledge about ageing alone is not sufficient to positively influence attitudes about working with older adults; rather, experiences during clinical practicum and

KEYWORDS

AGED CARE

CLINICAL

EDUCATION DEMENTIA

THIS ARTICLE HAS BEEN PEER-REVIEWED







Ronelle Hewetson (top), Petrea Cornwell (centre) and Susannah Davern

prior contact with older adults are critical to developing an interest in geriatric care (Andrews, Brodie, Andrews, Wong, & Thomas, 2005; Hobbs, Dean, Higgs, & Adamson, 2006). Little is known about speech pathology students' knowledge, confidence, and interest in working with older people, nor about factors that influence their interest in pursuing positions that specialise in service provision to older people. Therefore, this study explored two research questions, namely:

- What are speech pathology students' knowledge, confidence, and interest levels in working with older people prior to a clinical placement in adult services?
- 2. What impact do different placement settings (acute hospital, residential, out-patient rehabilitation) have on students' reported knowledge, confidence, attitudes, and interest in working with older people following a clinical placement?



Method Design

An observational cohort design, utilising a pre-post survey methodology, was used.

Participants



Anne E. Hill (top) and Lucy Hunter

A convenience sample of 74 participants provided informed consent and met the inclusion criteria of (a) being a speech pathology student at an Australian university, (b) who had completed academic courses in adult communication and swallowing disorders as part of their speech pathology degree, and (c) was due to undertake a clinical placement in an adult service. Participants were predominantly female (96%), reflective of the student cohort in speech pathology in Australia (Health Workforce Australia, 2014), and 70% were younger than 25. Fifty-two were enrolled in an undergraduate program and 22 in a graduate entry masters program. Twenty-six participants had completed a qualification prior to enrolling in the speech pathology program. Sixteen participants (22%) reported that they had no contact with medically unwell older people before starting their placement in an adult service, 44 reported some (48%) or a lot (11%) of contact with medically unwell older people not directly related to them, and 14 participants (19%) reported that prior contact was only with older family members. Of the 74 participants who completed pre-placement surveys, 52 also completed the post-placement survey following a clinical placement in an acute hospital setting (n = 25), in a residential setting exclusively or partly (n = 19), or in an out-patient rehabilitation setting (n = 8).

Procedure

Ethical approval was obtained from the research ethics committees of the relevant university and health service. All eligible students were invited to participate in the research by a university clinical education liaison manager through a blind copied group email that provided information on the study and directed those interested in participating to an on-line survey where they were prompted to create their own unique participant code. The students were informed that their participation was voluntary and that non-participation or request to withdraw would not result in any penalty, nor interfere with their current or future placement allocation. Consenting participants completed the survey and attitude scale by accessing a hyperlink contained in the study invitation email.

Data collection tools

Data were gathered through two instruments, both administered prior to and on completion of the placement. First, a survey "Confidence and interest in working with people 65 years and older" was purposefully developed by the research team. Part 1 of the survey gathered demographic information including age group, clinical placement setting, prior qualifications, and past clinical and non-clinical experience with an older population. Part 2 posed questions relating to perceptions about knowledge and confidence for working with an older population, as well as preferred future employment relating to caseload age and context. Item selection was informed through review of literature and practice guidelines (ASHA, 1988; SPA, 2005). Likert scales were used to gather information on perceptions of knowledge and confidence about (a) communication and swallow changes that occur as people grow older, (b) acquired communication disorders of motor speech, language, and cognitive-communication abilities, (c) dysphagia in medically well and medically complex older people, and (d) communication and swallowing changes specific to dementia. A preference ranking scale allowed for exploration of interest in future employment based on client age and practice setting, and items relating specifically to dementia were included. Pilot testing of the survey design and content was completed by four speech pathologists working with older people in acute and residential settings respectively.

The second instrument used, the University of California at Los Angeles Geriatrics Attitudes Scale (UCLA-GAS; Reuben et al., 1998), explored attitudes about older people. The UCLA-GAS is a 14-item, 5-point scale, in which a mean score above 3 is interpreted as a positive attitude. The UCLA-GAS has demonstrated a positive relationship between students' attitudes toward older people and interest in geriatrics as a career and has been shown to be sensitive to change over time (Reuben et al., 1998).

Data analysis

Data from the anonymous pre-coded instruments were entered into a spreadsheet and analysed using the Statistical Package for the Social Sciences. For research question 1, the total cohort (n = 74) was described in relation to initial responses to knowledge and confidence questions. A mean score on the complete UCLA-GAS was calculated for all participants. In addition, items that related specifically to interest in, and/or enjoyment of service provision to older people, were described individually in line with the aims of this study. Weighted group ranking scores for each item relating to future employment interests were reported, and were created by combining all participants' ranking scores for each item and then dividing the score by the number of participants.

Research question 2 was addressed by exploring change that occurred following a placement (n = 52) through comparison of aggregate scores of knowledge and confidence analysed using the Wilcoxon signed ranks test. Weighted ranking was used to report on future employment preference trends by comparing preand post-placement group weighted preference scores Analyses of interaction between placement setting and post-placement knowledge, confidence, and attitudes, were completed using a split-plot model ANOVA for 45 of the 52 participants who completed a placement in either (a) an acute hospital setting (n = 25) or (b) a placement that

was partly or exclusively in residential care settings (n = 19). Eight participants completed a placement in an out-patient rehabilitation setting and were excluded from this analysis as group numbers were low. Levine's test equality of error variances was used to examine whether assumptions of homogeneity were violated, which revealed no violation occurred on any variable.

Results

Knowledge about communication and swallowing in older people

In rating their pre-placement knowledge of communication and swallowing changes and disorders found in older people and people with dementia in particular (Figure 1), participants reported greater knowledge regarding age-related and acquired communication disorders than about swallowing changes and disorders. Knowledge about changes in swallowing due to dementia was rated the lowest, with 13 participants (17.5%) reporting no knowledge prior to commencing their placement.

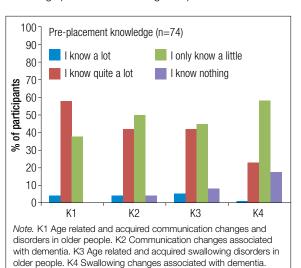


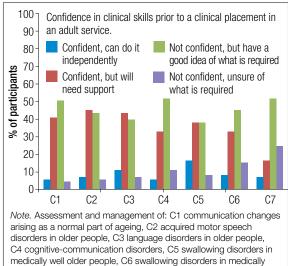
Figure 1. Students' reported knowledge pre-placement

Confidence in working with older people

Ratings of pre-placement confidence in management of age related and acquired communication disorders (Figure 2) revealed that participants reported the greatest degree of confidence in their ability to assess and manage adultacquired language disorders and swallowing disorders in medically well older people (54% felt confident to do either of these tasks independently or with some support [i.e., from a clinical educator]). The lowest confidence levels (not confident but with a good idea of what is required, or, not confident and unsure of what is required) were reported for cognitive-communication disorders (62.2%) and swallowing disorders secondary to dementia (75.7%).

Attitudes about older people

The pre-placement UCLA-GAS mean score for all participants (3.83±0.4) indicated that participants generally had a positive attitude about older people. Participants who reported prior contact with medically unwell older family members (n = 14) had a slightly more positive UCLA-GAS attitude score (3.98±0.3) than that of the total cohort. As presented in Table 1, most participants expressed positive attitudes about spending time with older people (79.7%) and about listening to information about their lives (91.8%).



complex older people, and C7 swallowing in people with dementia.



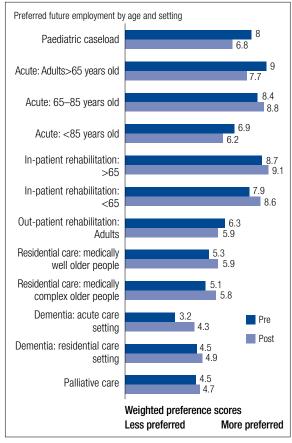


Figure 3. Students' preferred future employment: pre- and postplacement

Interest in working with older people

Pre-placement, a preference for working with younger people emerged from weighted ranked employment preferences based on setting and caseload age (refer to Figure 3). A trend of declining interest with increasing age of the client population was evident within the acute hospital setting, where working with adults younger than 65 was rated most favourably (group weighted preference score: 9), than with those between 65 and 85 years (preference score: 8.4), followed by those older than 85 (group weighted preference score: 6.9). The same trend was evident within a hospital-

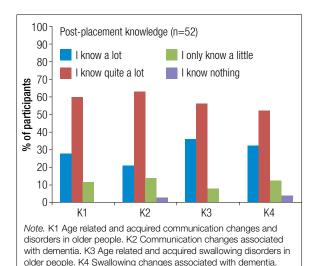
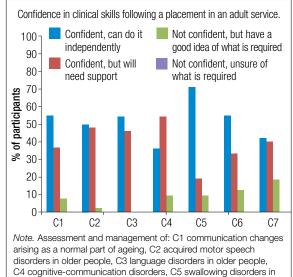


Figure 4. Students' reported knowledge post-placement

based rehabilitation setting. Twenty-nine participants (39%) ranked a paediatric caseload as their first employment preference, and 13 participants (17.5%) ranked a paediatric caseload as the least desirable option. Working with people on a palliative pathway or those with dementia, irrespective of setting, was rated least favourably.

Change in knowledge, confidence, attitudes, and employment interest following a clinical placement

Matched pre-post-placement surveys (n = 52) were analysed and revealed that participants demonstrated a statistically significant increase (p < 0.05) in their aggregate scores for knowledge and confidence in clinical skills across all items (refer to figures 3 and 4, and Table 2) following completion of a clinical placement in an adult service. Increased knowledge of, and confidence in, management of both communication (i.e., motor speech, cognitive-communication, and language impairments) and swallowing changes and disorders in an older population (i.e., in older



complex older people, and C7 swallowing in people with dementia.

Figure 5. Students' reported confidence post-placement (n = 52)

medically well older people, C6 swallowing disorders in medically

people who are medically well and medically complex, as well as those with dementia) occurred, with an evident shift towards feeling confident to complete tasks independently or with some support. As indicated in Table 2, a positive change in students' attitudes was noted, as measured on the UCLA-GAS; however, the change was not statistically significant.

Following an adult placement, future employment within a residential setting was rated more favourably than at pre-placement based on group weighted preference scores (refer to Figure 3). Working with people with dementia in hospital (pre-post preference scores: 3.2; 4.3) or residential setting (pre-post preference scores: 4.5; 4.9) increased. Working with people aged 65–85 was rated more favourably (group weighted pre-post scores: 8.4; 8.8), however working with people older than 85 declined in overall preference ranking (pre-post preference scores:

Table1: Pre- and post-placement responses of students on geriatric attitude scale							
	Agree or str	ongly agree	Neu	tral	Disagree or strongly disagree		
	Pre (%1)	Post (%)	Pre (%)	Post (%)	Pre (%)	Post (%)	
UCLA Geriatric Attitude Scale items	n = 74	n = 52	n = 74	n = 52	n = 74	n = 52	
Most old people are pleasant to be with.	79.7 ² 59	92.0 48	16.3 12	6.0 3	4.0 3	2.0 1	
If I have the choice, I would rather see younger patients than elderly ones.	31.1	19.2	35.1	40.4	33.8	40.4	
	23	10	26	21	25	21	
Medical care for old people uses up too much human and material resources.	4.0	3.8	10.8	6.0	85.1	90.4	
	3	2	8	3	63	47	
Taking a medical history from elderly patients is frequently an ordeal.	13.5	6.0	44.5	27.0	42.0	64.0	
	10	3	33	14	31	35	
Treatment of chronically ill old patients is hopeless.	2.7	2.0	13.5	7.6	83.8	90.4	
	2	1	10	4	62	47	
It is interesting listening to old people's accounts of their past experiences.	91.9	92.0	6.7	6.0	1.4	2.0	
	68	48	5	3	1	1	

¹ Percentage of students whose responses were in this category

² Items in italics reflect the % of participants with a positive attitude

Table 2. Change in students' reported knowledge, confidence, and attitudes post placement (n = 52)							
	Pre-placement	Post-placement	Wilcoxon Signed Rank test (z, p)				
Knowledge and confidence composite scores	Median1 (Range)	Median ¹ (Range)					
Knowledge about communication changes and disorders	5 (4–7)2	4 (2-6)2	-5.218, < .001*				
Knowledge about swallowing changes and disorders	6 (2-8)2	3 (2-7)2	-5.113, < .001*				
Confidence in managing communication changes and disorders	10 (4–15) ³	6 (4–10)3	-6.011, < .001*				
Confidence in managing swallowing changes and disorders	8 (3–12)4	4 (3-9)4	-5.589, < .001*				
Attitudes score	Mean⁵±SD	Mean ±SD					
UCLA Geriatric Attitude Scale score	3.83 ±0.42	3.93 ±0.40	-1.919, .05				

¹ A lower median reflects greater knowledge and confidence, ² Range: 2–8, ³Range: 4–16, ⁴Range: 3–12, ⁵A higher mean reflects a more positive attitude

^{*} Statistically significant change

Table 3. Reported knowledge and confidence following a placement solely in an acute setting or partly or exclusively in a residential setting						
		acute setting only : 19)	Placement partly or exclusively in a residential setting (n = 25)			
	Pre Mean ¹ ± SD	Post Mean ¹ ± SD	Pre Mean ¹ ± SD	Post Mean ¹ ± SD		
Knowledge about:						
Communication changes and disorders	2.32 (.47)	1.80 (.57)	2.58 (.50)	1.68 (.67)		
Communication changes secondary to dementia	2.64 (.56)	2.04 (.61)	2.58 (.60)	1.63 (.59)		
Dysphagia	2.40 (.64)	1.60 (.57)	2.68 (.82)	1.58 (.50)		
Swallowing changes secondary to dementia	2.84 (.62)	1.80 (.76)	2.79 (.71)	1.58 (.50)		
Confidence in assessment and management of:						
Motor speech disorders	2.32 (.55)	1.68 (.55)	2.63 (.76)	1.32 (.47)		
Aphasia	2.32 (.69)	1.56 (.50)	2.58 (.83)	1.37 (.49)		
Cognitive-communication disorders	2.60 (.81)	1.84 (.55)	2.79 (.63)	1.63 (.59)		
Dysphagia in medically well and medically complex adults	2.52 (.87)	1.36 (.56)	2.79 (.63)	1.58 (.69)		
Swallowing changes secondary to dementia	2.88 (.92)	1.72 (.67)	3.00 (.57)	1.53 (.69)		
¹ A lower mean reflects greater knowledge and confidence						

6.4; 6.2). Despite the increased preference for working with people with dementia, this client population remained within the three least preferred options, as did working with people on a palliative pathway.

Influence of placement setting

A split-plot model ANOVA yielded a main effect for time (pre- or post-placement) for knowledge of age-related communication changes or disorders, F(1,42)=32.38, p<0.001, and communication changes secondary to dementia, F(1,42)=43.52, p<0.001. However, no interaction effect between time and knowledge of communication changes in either group [F(1,42)=2.27, p=0.14; F(1,42)=2.19, p=0.15 respectively] was found. Similarly, a main effect for time was found for both dysphagia, F(1,42)=43.55, p<0.001, and swallowing changes related

to dementia, F(1,42)=63.58, p<0.001 with no interaction effect between time and knowledge of swallowing changes in either population [dysphagia: F(1,42)=1.12, swallowing changes in dementia: p=0.30; F(1,42)=0.37 p=0.55]. Therefore, knowledge in all areas improved irrespective of placement type. A placement partly or exclusively completed in a residential setting compared to an acute setting, resulted in mean scores (see Table 3) indicating greater knowledge of communication changes secondary to dementia but these findings were not significantly different.

A main effect for time was identified in participants' confidence in undertaking the assessment and management of a communication in disorders (see Table 3) such as; motor speech, F(1,42)=62.24, p<0.001; aphasia, F(1,42)=59.24, p<0.001, and cognitive-communication

disorders, F(1,42)=47.53, p<0.001. A significant interaction effect between time and placement type was only observed for motor speech disorders, F=7.43, p=0.01, and not for aphasia, F(1,42)=3.10, p=0.09, or cognitive-communication disorders, F(1,42)=2.05, p=0.16. The split-plot model ANOVA also revealed a main effect of time for confidence to assess and manage dysphagia in medically well and/or complex adults, F=30.33, p<0.001, and swallowing changes secondary to dementia, F=37.44, p<0.001 but no interaction for either population [F(1,42)=0.03, p=0.86; F(1,42)=1.11, p=0.30 respectively]. Analysis of change in attitudes did not yield a significant interaction with placement setting, F=0.73, p=0.40, but no main effect for time F=3.93, p=0.05.

Discussion

This study provided an exploratory investigation of speech pathology students' knowledge, confidence, attitudes towards, and interest in working with older people. Participants had a positive attitude towards older people as measured on the UCLA-GAS, more positive than has previously been reported for medical students and similar to other allied health students (Fitzgerald et al., 2006; Liu et al., 2012). Attitudes about older people in this study remained positive with a slight shift towards more positive attitudes following a clinical placement in an adult service, consistent with the findings of research linking attitude change to engagement in clinical learning (Robinson et al., 2006). Despite the participants' positive attitude towards older adults, they indicated a preference for working with younger adults. Some changes in employment preference trends occurred following a clinical placement in an adult service, with more positive rankings of working within a residential care setting, with adults between 65-85 years, people with dementia, and those on a palliative pathway. Given the changing profile of consumers of health and aged-care services in Australia, and the likely need for increased numbers of speech pathologists with the skills to provide services to medically complex populations, this finding is reassuring. Despite the more positive rating, working with people with dementia and those on a palliative pathway remained in the three least preferred options. The findings indicate a need to consider how the speech pathology profession can increase students' interest in these client populations.

Positive change also occurred in knowledge about, and confidence in, clinical skills related to communication and swallowing changes and disorders in an older population. This finding appears to highlight the value of clinical placements as a means for students to reinforce and add to their understanding of theory obtained during academic lectures through experiential learning on clinical placement. The importance of a clinical placement in an adult service, irrespective of placement setting, was shown in this study to add to the development of knowledge and skills, thereby demonstrating the crucial role of clinical placements in speech pathology student training. A trend was found in which participants who completed a placement partly or exclusively in a residential setting reported greater knowledge about swallowing difficulties associated with dementia than their peers who completed a placement solely in an acute hospital setting; however, the difference was not statistically significant.

A limitation of the current study is that variables that may account for this difference could not be controlled. In particular, between-group (placement type) differences in the students' knowledge about dementia may reflect client population or learning activity differences across the settings. It is less likely that participants would have had as much contact with medically well older people or people with dementia over a sustained period of time in a hospital setting as might have occurred in a residential setting. Unfortunately, activity level data and client demographic data was not collected in the current study. The findings of previous studies indicate that varied experiences with both well and unwell older adults that allow for repeated contact over time can influence interest in working with older populations (Cummings & Galambos, 2002; Koder & Helmes, 2008).

The influence of academic staff and clinical educators on student interest to work with older people could similarly not be controlled for or explored in the current study. A further limitation relates to the use of mailed surveys as attrition is an inherent challenge. Attrition in the current study was likely influenced by factors such as a decision not to offer incentives for participation and attempts to ensure anonymity as requests to participate were circulated via a group email to eligible participants rather than through personalised invitations to participant.

Implications of this study relate to future planning of clinical placements and curriculum content. The findings confirm that speech pathology students starting an adult placement are likely to have had varied prior contact with older people and to have different levels of knowledge and confidence. Clinical training that focuses specifically on an older client population may be an important component in developing the skills needed to provide high-quality speech pathology services to those 65 years and older. It would be important to explore the capacity of acute and residential services to provide clinical learning experiences that include contact with people with dementia and those who are on a palliative care pathway, as participants in this study reported low levels of confidence and interest in managing clients within these groups. Ideally, specialist teaching opportunities in aged care, residential, and/or hospitalbased dedicated units for people with dementia and those who are approaching end of life should be identified and supported.

For the profession to be responsive to the changing health context, it is important to consider how best to equip students to be not only competent but interested in working with older people. Further research that provides guidance on how to enhance academic content and clinical learning experiences to clearly elaborate on the distinctive service needs of older people is needed. Longitudinal studies to determine whether interest in working with older people translates to career choices in addition to student reflections of their experiences with older people during clinical practicum may identify placement components that need to be improved and/or maintained. Research into the impact of highly skilled role model clinicians on student interest would be valuable.

The findings of this study support initiatives that increase clinical exposure to older adults, where clinical competencies for specialising in service provision to older people are developed. Ideally, the essential role and growing need for speech pathology services to an older population group should be made explicit during clinical placements and embedded in curriculum content to align academic learning with service provision needs, thereby developing a future workforce with the knowledge, confidence, and interest in pursuing employment that specialises in elder care.

References

American Speech-Language-Hearing Association. (1988). The roles of speech-language pathologists and audiologists in working with older persons. *ASHA*, *20*, 80–84.

Andrews, G., Brodie, D., Andrews, J., Wong, J., & Thomas, B. (2005). Placement matters: Students' clinical experiences and their preferences for first employers. *International Nursing Review*, *52*(2), 142–153.

Australian Institute of Health and Welfare (AIHW). (2007). Older Australians at a glance (4th ed.). Canberra: Author. Burg, M., Waddell, R., Doty, R., Horne, C., Weilgas, C., & Davidson, R. (2001). Student interest in geriatric medicine. Gerontology & Geriatrics Education, 21(4), 1–12.

Cabre, M., Serra-Prat, M., Palomera, W., Almirall, J. & Pallare, R.(2010). Prevalence and prognostic implications of dysphagia in elderly patients with pneumonia. *Age and Ageing*, 39, 39–45.

Courtney, M., Tong, S., & Walsh, A. (2000). Acute-care nurses' attitudes towards older patients: A literature review. *International Journal of Nursing Practice*, 6(2), 62–69.

Cummings, S., Adler, G., & DeCoster, V. (2005). Factors influencing graduate social work students' interest in working with elders. *Educational Gerontology*, *31*, 643–655.

Health Workforce Australia. (2014). Speech pathologists in focus. Australia's Health Workforce Series. Canberra: Author. Hobbs, C., Dean, C., Higgs, J., & Adamson, B. (2006). Physiotherapy students' attitudes towards and knowledge of older people. Australian Journal of Physiotherapy, 52, 115–119.

Horner, J., Alberts, M. J., Dawson, D. V., & Cook, G. M. (1994). Swallowing in Alzheimer's disease. *Alzheimer Disease and Association Disorders*, 8(3), 177–189.

Kiely, D., & Simon, M. J. (2000). The protective effect of social engagement on mortality in long-term care. *Journal of the American Geriatrics Society*, 48(12), 1367–1372.

Koder, D. A., & Helmes, E. (2008). Predictors of interest in working with older adults: A survey of postgraduate trainee psychologists. *Gerontology & Geriatrics Education*, 29(2), 158–171.

Lin, L., Wu, S., Chen, H., Wang, T., & Chen, M. (2002). Prevalence of impaired swallowing in institutionalized older people in Taiwan. *Journal of American Geriatrics Society*, 55(7), 1118–1123.

Liu, Y., While, A. E., Norman, I. J., & Ye, W. (2012). Health professionals' attitudes towards older people and older patients: a systematic review. *Journal of Interprofessional Care*, 26, 397–409.

Productivity Commission. (2013). *An ageing Australia: Preparing for the future*. Commission Research Paper. Canberra.

Reuben, D. B., Lee, M., Davis, J. W., Jr., Eslami, M. S., Osterwel, D. G., Melchoire, S., & Weintraub, N. T. (1998). Development and validation of a geriatrics attitudes scale for primary care residents. *American Geriatrics Society*, 46(11), 1425–1430.

Robinson, A., Andrews-Hall, S., Fasset, M., Venter, L., Marlow, M., Cubit, K., ...Jongeling, L. (2006). *Building connections in aged care follow-up evaluation: Final report*. Hobart, Tas.: School of Nursing and Midwifery, University of Tasmania.

Speech Pathology Australia (SPA). (2012). *An inquiry into dementia early diagnosis and intervention*. Submission to The House of Representatives Standing Committee on Health and Ageing, May.

Speech Pathology Australia (SPA). (2005). *Productivity Commission Health Workforce Study: Speech Pathology Australia response*. Retrieved 6 Nov. 2014 from http://www.pc.gov.au/__data/assets/pdf_file/0009/10215/sub053.pdf

Ronelle Hewetson is a speech pathologist and PhD candidate with clinical education experience in South Africa and Australia. Petrea Cornwell is a speech pathologist in a conjoint research fellow position across MNHHS and Griffith University. Susannah Davern is a speech pathologist in residential aged care with Wesley Mission Brisbane. Anne Hill is a lecturer in speech pathology and clinical education program co-ordinator at The University of Queensland. Lucy Hunter is the clinical education liaison manager for speech pathology at The University of Queensland.

Correspondence to:

Ms Ronelle Hewetson

Speech Pathology Department, The Prince Charles Hospital, Rode Road, Chermside, 4032, QLD Australia phone: (07) 3139 6988

email: ronelle.hewetson@health.qld.gov.au

Being prepared for working in palliative care

The speech pathology perspective

Ashleigh Pascoe, Lauren J. Breen, and Naomi Cocks

KEYWORDS

END OF LIFE PALLIATIVE CARE

PREPAREDNESS FOR CLINICAL PRACTICE STUDENT

EDUCATION

THIS ARTICLE
HAS BEEN
PEERREVIEWED







Ashleigh Pascoe (top), Lauren J. Breen (centre) and Naomi Cocks

Providing quality palliative care services is a national priority, and speech pathologists play an integral role in this area managing communication and swallowing difficulties. However, very little is known about the type and amount of palliative care education currently incorporated into Australian speech pathology curricula and the preparedness of graduates to work in this field. This discussion paper summarises the role of the speech pathologist in palliative care and the preparedness of graduates to work in this field. Further research is required to develop a picture of the current educational practices in Australian speech pathology curricula.

alliative care services are provided to people diagnosed with a life limiting disease, where the possibility of a cure is rare or unlikely (CareSearch, 2013; World Health Organization (WHO), 2014). Clients with a range of conditions such as Parkinson's disease, cancer, dementia, motor neurone disease, and chronic obstructive pulmonary disease (COPD) are common in speech pathologists' caseloads (Eckman & Roe, 2005; Frost, 2001; Pollens, 2004; Roe & Leslie, 2010). Palliative care should not be viewed as occurring only at end-of-life; instead, the current palliative care philosophy advocates for its implementation early in the disease process in order to improve the quality of life for clients and their families (Pollens, 2012; WHO, 2014).

The provision of quality palliative care services is a national priority (The Australian Government Department of Health, 2010). Several studies recognise that palliative care involves an interdisciplinary team approach, and teamwork is necessary to ensure the palliative care concept is optimised (Crawford & Price, 2003; Morris & Leonard, 2007; Pollens, 2004). This team involves many professions, including both medical and allied health members (Pollens, 2012). In this paper we argue that speech pathologists have a crucial role in this team. In order to demonstrate this, we:

- outline the role of the speech pathologist in palliative care:
- describe what is known about the preparedness of Australian speech pathology graduates to work in palliative care; and

 highlight the need for more information about the preparedness of Australian-trained speech pathologists for working in palliative care.

The role of the speech pathologist in palliative care

As early as the late 1970s, the role of the speech pathologist in palliative care was identified (Potter, Schneiderman, & Gibson, 1979), and in recent years, has been well documented in the literature (Eckman & Roe, 2005; Frost, 2001; Pollens, 2004, 2012; Roe & Leslie, 2010; Roe, Leslie, & Drinnan, 2007; Toner & Shadden, 2012). Speech pathologists are employed in a variety of settings in which they may be involved in palliative care. This may include, but is not limited to, aged-care facilities, acute hospitals, community outpatient clinics, and hospices (Eckman & Roe, 2005; Pollens, 2004).

The role of the speech pathologist in palliative care was summarised by Pollens (2004). She proposed that the role involved communication, cognition, and/or dysphagia management in order to maintain and/or improve the client's quality of life. This role also involved a consultative component between client, caregivers, and the medical team (Pollens, 2004). Our role as speech pathologists may include, but is not limited to, bedside dysphagia assessments and assessing a patient's communication skills (Pollens, 2004; Potter et al., 1979). A poignant example from the literature where the speech pathologist had successful involvement in palliative care is:

Mr. E had marked cognitive and communication difficulties, and was exhibiting anger towards caregivers when they could not understand his requests. The hospice nurse referred for a speech-language pathology consult. The speech-language pathologist determined that Mr. E was not able to use reading or picture stimuli as a communication mode, but that yes/no questions remained reliable. The daughter was instructed in the use of topic choices for determining her father's intended message. The nurse and daughter understood his limitations, which supported their role as caregivers. (Pollens, 2004, p. 697)

Pollens (2004, 2012) stated that speech pathologists are often not viewed as a regular inclusion in the management of palliative patients, and instead may be consulted on a case-by-case basis. Whether this viewpoint is only adopted in the literature, in practice, or both, is unknown.

An increasingly ageing Australian population and improved medical management of chronic and progressive conditions, highlights the need to recognise the role and expertise speech pathologists can contribute along the length of the palliative care trajectory (Australian Institute of Health and Welfare, 2012).

The preparedness of speech pathology graduates to work in palliative care

Although the literature highlights the importance of the speech pathologist's role in palliative care, consideration is needed about how best to prepare speech pathology students to work in palliative care in order to promote holistic management along the entire disease trajectory. Providing palliative care education and opportunities will not only better prepare students and new graduates for their emotional response to working with people who are dying, but will also inform them of their potential role in this area (Eckman & Roe, 2005; Roe & Leslie, 2010).

Research suggests that professionals who have received minimal or no training in palliative care are those most at risk of experiencing personal and professional obstacles (Keidel, 2002; Melo & Oliver, 2011; Murray Frommelt, 2003; Rivers, Perkins, & Carson, 2009). A systematic review of the literature showed that a lack of training increases the risk of workplace stress and burnout in death and dying contexts (Truffelli et al., 2008), while the presence of education has a protective effect against these deleterious outcomes for clinicians working in palliative care settings (Lobb et al., 2010). If university students have an understanding of death and the dying process, this may help to alleviate the grief and anxiety that can be associated with the loss of a patient (Toner & Shadden, 2012).

An understanding of illness trajectories, the dying process, death itself, and the emotional, psychological, and physical changes associated with these processes, may also better prepare students for work with patients with palliative needs, and the manner in which they manage these clients (Buchanan et al., 2012; Harper, 1997; Potter et al., 1979; Toner & Shadden, 2012). It has been suggested that having a thorough understanding of grieving processes can also be helpful in the planning and delivery of palliative management. Grief is an individualised response. Due to this, the more familiar clinicians are with the grieving process and the emotions, behaviours, and the variations they may experience, the better equipped they may be to address the patient's and family's needs (Potter et al., 1979). The grieving process and death are complex concepts and entities that intertwine with a person's worldview. Learning about these concepts in a supportive environment, such as the university setting, may help to mature students' understanding and acceptance (Teed & Keating, 2009).

An Australian national scoping study investigated the prevalence of palliative care content in undergraduate medical and health care curricula (Hegarty et al., 2010). This study found that, in general, palliative care content was incorporated into the specified courses; however, there was noted variation between the "nature and extent of inclusion of palliative care, and the teaching and learning approaches used" (Hegarty et al., 2010, p. 105). It is worth noting that speech pathology was not investigated in the study, and that in allied health courses in which palliative care was addressed, it was often not addressed in depth.

This highlights that the information received at the university level in Australia may not be adequate to prepare students for practice in palliative care. To date, there is currently no Australian research that details the amount or content of palliative care information included in speech pathology university courses.

There have been several reasons suggested as to why palliative care is currently not incorporated into health professional course curricula. These include overcrowded curricula and a lack of specialised knowledge by teaching staff and available placement experiences (Cairns & Yates. 2003; Hegarty et al., 2010). To overcome this void, the Australian Government Department of Health and Ageing funded the Palliative Care Curriculum for Undergraduates (PCC4U) project to develop the skills of health professionals in palliative care. A study by Mathisen, Yates, and Crofts (2010) investigated the incorporation of this program into the final-year undergraduate speech pathology curricula at the University of Newcastle, New South Wales. This study confirmed the importance of including palliative care content into speech pathology curricula, and highlighted that the undergraduate students found it to be a worthwhile learning experience (Mathisen et al., 2010). It is possible that other Australian speech pathology courses have utilised the PCC4U program, but to our knowledge no results of any such initiatives have been published.

Students have been reported to be concerned about the progression or death of a client, and believe that it would affect their personal and professional lives (Rivers et al., 2009). Studies that have investigated the experiences of students who participated in palliative care education have found it to be a worthwhile experience, with education at the university level resulting in improved competence (Bush & Shahwan-Akl, 2013), positive attitudes (Anderson, Williams, Bost, & Barnard, 2008; Kumar, Jim, & Sisodia, 2011), improved self-awareness and personal development (Ballesteros, Centeno, & Arantzamendi, 2014), and increased knowledge (Anderson et al., 2008; Ballesteros et al., 2014; Kumar et al., 2011) in relation to palliative care.

Summary

In summary, there appears to be a dearth of literature on palliative care education in speech pathology curricula. While Mathisen et al.'s (2010) study makes a valuable contribution to the literature, there remain several unanswered questions regarding (a) the extent of palliative care information across Australian speech pathology curricula, (b) the preparedness of Australian-trained speech pathologists for working in palliative care, and (c) how practising speech pathologists believe universities could improve their palliative care curriculum. Speech pathologists need to have an acceptable level of competence in this challenging area, yet little is known about the palliative care education currently incorporated into Australian speech pathology curricula (whether as a standalone unit or integrated throughout several units within a course) and the preparedness of graduates to work in this field. For this reason, further research is required to develop a picture of the current educational practices in Australian speech pathology curricula.

References

Anderson, W., Williams, J., Bost, J., & Barnard, D. (2008). Exposure to death is associated with positive attitudes and higher knowledge about end-of-life care in graduating medical students. *Journal of Palliative Medicine*, *11*(9), 1227–1233.

Australian Government Department of Health. (2010). The National Palliative Care Strategy: Supporting Australians to live well at the end of life. Retrieved 11 Nov. 2013, from http://www.health.gov.au/internet/main/publishing.nsf/Content/A87BC5583161BEBFCA257BF000 1D3AF6/\$File/NationalPalliativeCareStrategy.pdf

Australian Institute of Health and Welfare. (2012). Palliative care services in Australia 2012. Canberra: Author. Ballesteros, M., Centeno, C., & Arantzamendi, M. (2014). A qualitative exploratory study of nursing students' assessment of the contribution of palliative care learning. Nurse Education Today, 34(6): e1–6. doi: 10.1016/j. nedt.2013.12.010

Buchanan, A., Cooper, I., Fielding, A., Freegard, H., Godwin, S., Hird, K., ... Soulos, T. (2012). End of life. In H. Freegard & L. Isted (Eds.), *Ethical practice for health professionals* (2nd ed.); (pp.332–334). Melbourne, Vic.: Cengage Learning.

Bush, T., & Shahwan-Akl, L. (2013). Palliative care education: Does it influence future practice? *Contemporary Nurse*, *43*(2), 172–177.

Cairns, W., & Yates, P. (2003). Education and training in palliative care. *Medical Journal of Australia*, 179(6), 26.

CareSearch. (2013, 28 June). What is palliative care? Retrieved 24 July 2014, from http://www.caresearch.com.au/caresearch/WhatisPalliativeCare/tabid/63/Default.aspx

Crawford, G. B., & Price, S. D. (2003). Team working: palliative care as a model of interdisciplinary practice. *Medical Journal of Australia*, 179(6), 32–34.

Eckman, S., & Roe, J. (2005). Speech and language therapists in palliative care: What do we have to offer? *International Journal of Palliative Nursing*, 11(4), 179–181.

Frost, M. (2001). The role of physical, occupational and speech therapy in hospice: Patient empowerment. *American Journal of Hospice and Palliative Medicine*, 18(6), 397–402.

Harper, B. (1997). Growth in caring and professional ethics in hospice. *The Hospice Journal*, 12(2), 65–70.

Hegarty, M., Currow, D., Parker, D., Turnbull, B., Devery, K., Canning, D., ... Yates, P. (2010). Palliative care in undergraduate curricula: Results of a national scoping study. *Focus on Health Professional Education*, *12*(2), 97–109.

Keidel, G. C. (2002). Burnout and compassion fatigue among hospice caregivers. *American Journal of Hospice and Palliative Care*, 19(3), 200–205.

Kumar, S., Jim, A., & Sisodia, V. (2011). Effects of palliative care training program on knowledge, attitudes, beliefs and experiences among student physiotherapists: A preliminary quasi-experimental study. *Indian Journal of Palliative Care*, *17*(1), 47–53.

Lobb, E. A., Oldham, L., Vojkovic, S., Kristjanson, L. J., Smith, J., Brown, J. M., & Dwyer, V. W. J. (2010). Frontline grief: The workplace support needs of community palliative care nurses after the death of a patient. *Journal of Hospice and Palliative Nursing*, 12, 225–233.

Mathisen, B., Yates, P., & Crofts, P. (2010). Palliative care curriculum for speech-language pathology students. *International Journal of Language and Communication Disorders*, 46(3), 273–285.

Melo, C. G., & Oliver, D. (2011). Can addressing death anxiety reduce health care workers' burnout and improve care? *Journal of Palliative Care*, *27*(4), 287–295.

Morris, J., & Leonard, R. (2007). Physiotherapy students' experiences of palliative care placements: Promoting interprofessional learning and patient-centred approaches. *Journal of Interprofessional Care*, *21*(5), 569–571.

Murray Frommelt, K. H. (2003). Attitudes toward care of the terminally ill: An educational intervention. *American Journal of Hospice and Palliative Care*, 20(1), 13–22.

Pollens, R. (2004). Role of the speech-language pathologist in palliative hospice care. *Journal of Palliative Medicine*, 7(5), 694–702.

Pollens, R. (2012). Integrating speech-language pathology services in palliative end-of-life care. *Topics in Language Disorders*, *32*(2), 137–148.

Potter, R., Schneiderman, R., & Gibson, G. (1979). Understanding death, dying, and the critically ill: A concern for speech-language pathologists. *Journal of Communication Disorders*, *12*, 495–502.

Rivers, K. O., Perkins, R. A., & Carson, C. P. (2009). Perceptions of speech-pathology and audiology students concerning death and dying: A preliminary study. *International Journal of Language and Communication Disorders*, 44(1), 98–111.

Roe, J., & Leslie, P. (2010). Beginning of the end?: Ending the therapeutic relationship in palliative care. *International Journal of Speech-Language Pathology*, 12(4), 304–308.

Roe, J., Leslie, P., & Drinnan, M. (2007). Oropharyngeal dysphagia: The experience of patients with non-head and neck cancers receiving specialist palliative care. *Palliative Medicine*, *21*, 567–574.

Teed, R., & Keating, J. (2009). Palliative care education in Australian physiotherapy undergraduate curriculum. Retrieved 15 Sept. 2014, from http://www.caresearch.com.au/caresearch/Portals/4/Documents/Report on Physiotherapy Palliative Care Curriculum_.pdf

Toner, M., & Shadden, B. (2012). End of life: An overview. *Topics in Language Disorders*, 32(2), 111–118.

Truffelli, D. C., Bensi, C. G., Garcia, J. B., Narahara, J. L., Abrao, M. N., Diniz, R. W., & Del Giglio, A. (2008). Burnout in cancer profressionals: A systematic review and meta-analysis. *European Journal of Cancer Care*, *17*, 524–531.

World Health Organization (WHO). (2014). WHO Definition of Palliative Care. Retrieved 10 Nov. 2014, from http://www.who.int/cancer/palliative/definition/en/

Ashleigh Pascoe is a speech pathologist and Clinical Coordinator at Curtin University. She is currently completing her Masters by research in palliative care. **Dr Lauren J. Breen** is a senior lecturer in psychology at Curtin University. Her research areas include grief and palliative care. **Dr Naomi Cocks** is a senior lecturer in acquired communication and swallowing disorders at Curtin University.

Correspondence to:

Ashleigh Pascoe

Speech Pathologist and Clinical Coordinator Curtin University, Bentley GPO Box U1987, Perth WA 6845 phone: (08) 9266 7860



Educating a future aged-care workforce

Shaping positive attitudes and developing collaborative practice capabilities

Jade Cartwright, Brooke Sanderson, Anne Whitworth, Elizabeth Oliver, and Nigel Gribble

To deliver quality care to increasing numbers of older Australians, it is imperative that health education programs are designed to ensure graduates are equipped with the knowledge, skills, and attitudes required for employment in residential aged-care settings. An innovation is set out here that aimed to deliver a high-quality interprofessional practice placement to speech-language pathology and occupational therapy students within a residential aged-care facility, whereby students were trained to deliver a quality-of-life enrichment program, the Ashby Memory Method™, to residents on an individual basis. The findings of the study were positive, with students valuing the learning experience and demonstrating positive shifts in attitudes, confidence, and collaborative practice capabilities. Positive outcomes were also demonstrated for the organisation and its residents. The findings provide direction for future research and high-quality aged-care clinical placement models with potential to drive future workforce development.

ver one million Australians currently receive agedcare services, with that number projected to increase to over 3.5 million by 2050 (Productivity Commission, 2011). While the range of aged-care services have improved in recent decades, the quality of care remains highly variable and fundamental reform is required to better meet the needs of an older and increasingly diverse Australian population (Productivity Commission, 2011). Major challenges facing the sector have been identified, including the growing demand for services, shifts in the type of care demanded, and the need to expand the aged-care workforce (Abbey et al., 2006; Productivity Commission, 2011). There is concern among policy-makers and service providers about retaining existing staff and attracting new staff to the sector (Grealish et al., 2013; Productivity Commission, 2011).

The workforce challenge

It has been estimated that the aged-care workforce will need to quadruple by 2050 to meet the growing demand for aged-care services (Productivity Commission, 2011). Attracting health professionals to the sector is however problematic, with health graduates viewing aged care as a lower status career choice and undesirable career destination (Abbey et al., 2006; Xiao, Paterson, Henderson, & Kelton, 2008). The positive and innovative opportunities within the sector are often overlooked and the specialised skills required underappreciated (Neville, Yuginovich, & Boyes, 2008). Efforts to improve career pathways, opportunities for high-quality professional development, and wage parity are required to increase the willingness of health workers to enter the sector (Abbey et al., 2006; Productivity Commission, 2011). Furthermore, adequately preparing and inspiring students as aged-care champions is seen as a key strategy for workforce development (Grealish et al., 2013; Neville et al., 2008).

Training a future health workforce

Providing students with positive clinical learning experiences within residential aged-care facilities presents an opportunity to shape attitudes and redirect career preferences (Abbey et al., 2006; Health Workforce Australia (HWA), 2011; Robinson, Abbey, Abbey, Toye, & Barnes, 2009). However, the provision of successful clinical placements represents another challenge to the aged-care sector (Robinson, Andrews-Hall, & Fassett, 2007); they are reportably underutilised with few appropriately qualified staff to supervise students within this setting (Barnett et al., 2012; Robinson et al., 2007). As a result, students often report low levels of support and can find the experience challenging and daunting (Robinson et al., 2006). Negative placement experiences then run the risk of entrenching negative attitudes towards aged care, failing to address workforce priorities (Abbey et al., 2006).

Previous research, most notably within nursing, has explored factors that promote quality aged-care learning environments. Enablers of student satisfaction include adequate pre-clinical preparation and orientation, effective supervision and mentorship, adequate resources and infrastructure, sense of belonging, clear roles and responsibilities, opportunities for team work, and a culture of quality and person-centred care (Abbey et al., 2006; Levett-Jones, Lathlean, McMillan, & Higgins, 2007; Robinson et al., 2007; Robinson et al., 2009; Siggins Miller Consultants, 2012). Conversely, placements concerned

KEYWORDS

AGED CARE

EDUCATION DEMENTIA

INTER-PROFESSIONAL EDUCATION

INTER-PROFESSIONAL PRACTICE

THIS ARTICLE
HAS BEEN
PEERREVIEWED







Jade Cartwright (top), Brooke Sanderson (centre) and Anne Whitworth

Table 1. Outcome measures						
Level of educational outcome (McNair et al., 2005)	Outcome measure	Description				
Level 1: Students' reaction to and satisfaction with the placement	Placement evaluation survey	SLP students completed an anonymous online placement survey at the end of the placement block. Students responded to 15 statements on a 5-point Likert scale, ranging from 1 (strongly disagree) to 5 (strongly agree).				
Level 2: Attitudes and learning	Confidence rating scale	A confidence rating scale was developed for this study, completed by all students pre- and post- placement. Students responded to 10 statements on a 5-point Likert scale, ranging from 1 (I feel very unconfident) to 5 (I feel very confident).				
Level 3: Change in interprofessional behaviours	Interprofessional Capability Assessment Tool (ICAT; Brewer, Gribble, Robinson, Lloyd, & White, 2009)	The ICAT was completed by the clinical educator to rate students' skills at mid- and end- placement across four capability areas of communication, professionalism, collaborative practice, and client-centred service / care (Brewer & Jones, 2013). For each capability area, skills were graded as unsatisfactory, developing, at the required standard, or excellent. At the required standard equates to 'entry level' or the performance expected for graduation from an undergraduate or graduate entry masters course.				
Level 4: Change in organisational practice and benefits to residents	Focus groups and semi- structured interviews	Student focus groups and semi-structured interviews with staff and family members were completed post-placement to collect qualitative feedback about the placement and service innovation.				





Elizabeth Oliver (top) and Nigel Gribble

with mastery of "basic skills" or routine care delivery are more likely to discourage students from working with older people (Abbey et al., 2006).

Interprofessional education

Interprofessional education has been identified as one of the most promising solutions for equipping a future aged-care workforce with the knowledge, attitudes, and collaborative practice capabilities required to provide better quality care (D'Amour & Oandasan, 2005; HWA, 2011; Reeves et al., 2009; World Health Organization (WHO), 2010). Interprofessional education and interprofessional practice (IPP) placements train a new type of health worker who is ready to solve problems, move beyond routine care delivery, and look towards new ways of delivering safe and effective health services. Through developing collaborative practice capabilities students can be empowered to take on leadership roles and strengthen their sense of social responsibility to service the needs of clinical populations that have been traditionally underserved (McNair, Stone, Sims, & Curtis, 2005).

The current innovation

The current innovation sought to design, implement, and evaluate an IPP placement for speech-language pathology (SLP) and occupational therapy (OT) students that would be received positively, while enabling mastery of collaborative practice capabilities. In developing the placement model, university and organisation staff worked in partnership to design a structured experience that would add value to the organisation and its residents by addressing an identified service gap. This concerned the organisation's limited capacity to deliver interventions to residents on an individual basis. The organisation selected the Ashby Memory Method (AMM™), a quality-of-life enrichment program for people with mild to moderate dementia that could be delivered by trained students under the mentorship of organisation staff (Ashby, Buss, Firmstone, & Brand, 2008). The students were engaged as leaders and active collaborators in the innovation and the placement was strategically designed to be of mutual benefit, preparing the

future aged-care workforce, while expanding services within the participating aged-care organisation.

Methods Participants

Ten SLP and 10 OT students were allocated to the aged-care placement as part of the university fieldwork allocation process. All students were female and in the final year of their course. Ethics approval was obtained from the university Human Research Ethics Committee and all 20 students provided written consent to participate. Five organisation staff and five family members also consented to participate in the study.

Placement schedule

The placement was structured around the 22-week AMM™ intervention, consisting of two 11-week SLP placement blocks and two 7-week and one 8-week (extended to cover the AMM™ intervention sessions) OT placement blocks. Five students from each discipline attended the placement at a time. Students were supported and mentored by the organisation's senior OT and university academic staff. The senior OT was also the nominated clinical educator who completed the students' evaluations.

Student orientation and training

Students were provided with pre-placement information outlining the aims of the placement and the role that they were playing in the service innovation. Prior to commencing the placement, students completed an online training package, learning how to deliver the AMMTM intervention (Ashby et al., 2008). Students were orientated to the facility and the aims of the innovation on the first day of their placement.

Intervention schedule and clinical learning activities

Each student was partnered with two residents who were recruited to a separate arm of the study evaluating resident outcomes that will be reported in a future paper. Students worked with residents twice weekly for 45–60 minutes. Each resident received a total of 22 weeks of AMMTM

Statement	% Agreemen
Satisfaction with overall fieldwork experience	
Sufficient details were provided by the agency prior to the placement commencing	90%
was orientated to the staff and agency and was made to feel welcome	100%
The roles of the student and the clinical educator were negotiated so both parties had a clear understanding of their needs and expectations	100%
The student and clinical educator discussed the student's specific learning goals for the placement	70%
The student and the clinical educator were clearly aware of the University's requirements for the placement	90%
The clinical educator and the student were able to access quality support from other staff, students and the University when appropriate	100%
There were sufficient clinical learning opportunities for the student	70%
Satisfaction with support provided by clinical educator	
My clinical educator encouraged me to apply my theoretical knowledge	100%
My clinical educator was sensitive and responsive to my needs	90%
Balanced feedback which was timely, useful and accurate was provided	90%
Feedback was based on data collected from a sufficient range of clinical activities / performance indicators	100%
An effective and non-threatening teaching relationship was established which was collegial and respectful of both student and clinical educator	90%
The clinical educator encouraged the student to extend their applied theoretical knowledge, clinical, and professional communication skills	100%
Self-evaluation by the student was an integral and valued component of supervision	90%
Supervision was compatible with the student's need for independence and support	90%

intervention, with students handing over to a new student at the end of each placement block. Students worked collaboratively to plan sessions and complete reflection tasks. Additional learning opportunities were provided (e.g., education sessions, planning additional group activities).

Outcome measurement

Outcome measures are described in Table 1 with reference to an adapted version of Kirkpatrick's (1967) evaluation framework (McNair et al., 2005). Only SLP students completed the placement evaluation survey and Interprofessional Capability Assessment Tool (ICAT). Student focus groups and semi-structured interviews with staff and family were conducted by members of the research team and were recorded and transcribed verbatim.

Data analysis

The study employed a descriptive and qualitative analysis. Where pre- and post- scores were available (i.e., students' confidence ratings), Wilcoxon Signed Ranks Tests were used to evaluate change. Qualitative data were analysed thematically drawing on the principles of Braun and Clarke (2006). Nvivo9 was used for data management and coding. Agreement was reached on the themes through review and discussion by the research team.

Results

Outcome level 1

Of the 10 SLP students who completed the placement evaluation, 9 rated the overall learning experience as positive, while 1 student rated the experience as outstanding. The satisfaction ratings are presented in Table 2 with the proportion of students that either agreed or strongly agreed with each statement. Thirteen of the 15 statements achieved agreement of 90–100%.

Outcome level 2

The students' confidence ratings increased from pre- to post- placement, with the mode and range for each statement provided in Table 3. The total number of statements students rated as *confident* or *very confident* increased from 129 pre-placement (64.5%) to 192 post-placement (96%). Wilcoxon Signed Ranks Tests revealed that students' confidence working in the aged-care setting increased significantly as a result of the placement across both knowledge (z = 3.92, p < .001) and practical skills (z = 3.95, p < .001).

Outcome level 3

ICAT data was available for 9/10 SLP students. At the end of the placement, all students demonstrated entry level

Table 3. Students' confidence ratings pre- and post-placement							
Statement	Pre-mode (Range) n = 20	Post-mode (Range) n = 20					
Confidence in knowledge and understanding							
I have a sound understanding of the model of care in the aged care sector	3 (1–3)	4 (4–4)					
I have a sound understanding of challenges faced by the aged care sector in the delivery of health care services	3 (1–4)	4 (4–5)					
I have a sound knowledge of the speech pathologists role in working with people with cognitive difficulties	4 (1–4)	4 (4–5)					
I have a sound knowledge of the occupational therapists role in working with people with cognitive difficulties	4 (1-4)	4 (3–5)					
I have a sound understanding of the key competencies required for effective interprofessional practice	4 (2–4)	4 (4–5)					
I have a sound knowledge of the cognitive difficulties experienced by adults	4 (2-4)	4 (3–5)					
I understand the impact of cognitive difficulties on communication outcomes	4 (2-4)	4 (3–5)					
I understand evidence based approaches to facilitate the cognitive, communication and quality-of-life outcomes for adults with cognitive difficulties	3 (2–4)	4 (3–5)					
Confidence in practical skills							
I am able to apply practice strategies to make a valuable contribution to the interprofessional practice team	4 (2–4)	4 (3–5)					
I am able to apply practical strategies to facilitate the cognitive, communication and quality-of-life outcomes for adults with cognitive difficulties	3 (2–4)	4 (4–5)					
Note. Rating on a 5-point Likert scale, 1 = I feel very unconfident, 5 = I feel very confident.							

skills across all collaborative practice capabilities. The overall capability rating was at the required standard for 60% of students and rated as excellent for 40% of students

Outcome level 4

Qualitative feedback from staff identified that the placement was positively received and successful in building capacity for one-to-one interventions without placing undue burden on the organisation: "I think we had six hundred hours of intervention time by having those students. It's just phenomenal" (staff member). Family members were positive about the clinical placement and service innovation, appreciating the personal attention and care that their loved one received. Staff enjoyed working collaboratively with the students and valued their "creativity" and "fresh ideas". Organisation staff also learnt more about the role of SLP in aged care and the importance of communication.

Students, staff, and family members perceived a range of positive benefits for residents. The most prominent theme related to the enjoyment residents gained from spending time with the students: "It was evident that positive relationships were quickly formed between the residents and the students and that the residents looked forward to the visits" (staff member). The innovation also provided a sense of purpose and self-worth for the residents, enjoying the opportunity to "teach the students" and "help with their careers". Students reported perceived benefits for the residents' memory, confidence, self-esteem, and mood, for example, one student commented: "I noticed especially with one of my clients just the confidence because when you're delivering AMM it's all about that positive engagement and praise and building that confidence".

Qualitative analysis of the student experience

The student reflections following the placement provided rich data regarding the student experience. Identified themes capture the valued aspects of the placement.

Clinical placements in the aged-care setting are rewarding

The students gained reward from giving to the residents, seeing improvements in the residents' memory, confidence, and well-being, and having the opportunity to build genuine relationships and rapport. Students described the placement as "wonderful", "fun", "uplifting", and "motivating". They valued the unique opportunity to spend quality time with individual residents. Students reported increased interest in dementia and more positive attitudes towards aged care as a future career destination. Students were unanimous that they would recommend the placement to others and valued being part of the service innovation.

Supportive clinical learning environment

Students expressed positive views on the learning experience, its structure and content, and the quality of clinical education provided. They described their clinical educator as "welcoming", "knowledgeable", "flexible", "passionate", and "inspiring". Students valued the opportunity for leadership and to work independently with residents: "Being able to, I suppose, have that one-on-one time where you can kind of experiment a little bit". Students noted "ample learning opportunities" to "self-reflect", "develop clinical and interprofessional skills", and "extend

knowledge"; however, some recommended inclusion of more discipline-specific learning opportunities. The students valued receiving AMM™ training and developing competency in a specific intervention. Students identified that a dedicated student room and internet access would have further enhanced the learning environment.

Positive shifts in collaborative practice capabilities and clinical skills

Students valued the opportunities for interprofessional learning and teamwork, perceiving positive shifts in their collaborative practice capabilities and clinical skills. Students consistently reported enhanced confidence in their rapport-building and communication skills as a result of the quality time spent with the residents. One student commented directly that while she was initially anxious about communicating with and relating to older adults, including those with dementia, this was not the case at the end of the placement. Another commented: "It's nice to spend that quality time with someone as well because it really facilitated other skills in us like developing rapport ... which really helped us and again you feel more competent with those skills".

Positive shifts in interprofessional socialisation and values were evident, with students reporting an increased understanding of their respective roles. Students valued the opportunity to build teamwork capabilities through collaborative problem-solving, reflection, and session planning.

Discussion

This innovative project aimed to provide SLP and OT students with positive exposure to aged care through a high-quality IPP placement experience. A secondary aim was to increase capacity for the organisation to provide one-to-one interventions to residents, with the placement supporting a service innovation of mutual benefit to students, residents, and the organisation. Positive outcomes were achieved across all four levels of the adapted Kirkpatrick evaluation framework, providing valuable insights into the design of a high-quality clinical experience within a residential aged-care setting.

Student outcomes

Students were highly satisfied with the placement, valuing the learning experience and demonstrating positive shifts in attitudes, confidence, and collaborative practice capabilities. This is consistent with previous research, supporting a strong relationship between students' perception of satisfaction within a clinical placement and their overall success within that placement (Abbey et al., 2006). Unlike previous studies (Robinson et al., 2007; Abbey et al., 2006), the students' attitudes towards the aged-care setting were consistently positive. While a number of students acknowledged being apprehensive coming into the placement, the quality time spent with residents and supportive learning environment increased their level of comfort and interest in the setting. Furthermore, the students valued the opportunity to be trained in and develop competency delivering the $\mathsf{AMM}^{\scriptscriptstyle\mathsf{TM}}$ intervention, which facilitated enhanced communication and rapport-building skills. Students contributed actively to the service innovation, adopting leadership roles and recognising the additional value to the organisation and its residents. Providing such intrinsic rewards and the opportunity for both professional and personal growth were identified as key enablers of the placement's success.

Organisation and resident outcomes

The successful outcomes achieved at the organisational level demonstrate that structured and strategically designed placement models can successfully build capacity for service innovation within the aged-care sector. A significant increase in the provision of one-to-one intervention was achieved, which resulted in perceived benefits for the residents' cognitive function, social relationships, confidence, and well-being. This is in contrast to previous research where student placements have increased strain on organisation staff (Robinson et al., 2007). The organisation viewed the students as adding value and innovation to their services, thus contributing to the organisation winning a 2014 Better Practice Award (Australian Aged Care Quality Agency) in the resident lifestyle category. This positive outcome highlights the potential benefits of universities establishing strong collaborative partnerships with aged-care organisations to support the design and delivery of effective clinical placement models.

Limitations and future directions

The current study has a number of limitations that should be addressed in future research, most notably, the small sample size and the lack of a control group. The clinical placement model should be replicated in other aged-care facilities to further test its effectiveness. A future study may also compare the delivery of the AMMTM intervention to student visits alone, to determine whether it was the social relationships formed or more specific components of the AMMTM intervention that facilitated positive outcomes for both students and residents. Future expansion of the clinical placement model should explore ways to incorporate more discipline-specific supervision and learning opportunities. The outcomes for residents should also be examined in more detail and will be the focus of a separate paper.

A positive finding to emerge from the study concerns the organisation's increased appreciation of the role of SLP in aged care. The CEO of the organisation stated the placement "broadened our perspectives on the role of the speech pathologist with relation to older adults, particularly with regard to communication intervention". Future studies should build on this finding, using similar innovations as an opportunity to raise the profile of the profession, while simultaneously attracting graduates to the sector. This may have influential secondary outcomes, supporting the creation of new positions and increased funding allocation to communication and other SLP services.

Conclusion

The current study demonstrated the viability of high-quality clinical learning experiences in a residential aged-care setting. The placement was well received by students, residents, and organisation staff, allowing students to increase confidence and develop entry-level collaborative practice capabilities. The clinical placement model was also successful in increasing organisational capacity for service quality and innovation, ensuring continuation of the placement in subsequent years which has included expansion of services provided by SLP and OT students within the organisation. The findings provide direction for replication of the clinical placement model within other facilities and a strong platform for future research. The findings also demonstrate the important role that the tertiary sector plays in aged-care reform and workforce development innovation.

References

Abbey, J., Abbey, B., Bridges, P., Elder, R., Lemcke, P., Liddle, J., & Thornton, R. (2006). Clinical placements in residential aged care facilities: The impact on nursing students' perception of aged care and the effect on career plans. *Australian Journal of Advanced Nursing*, 23(4), 14–19.

Ashby, J., Buss, J., Firmstone, D., & Brand, S. (2008). Efficacy of a cognitive intervention for the therapeutic treatment of mild to moderate Alzheimer's disease. Retrieved 11 Feb. 2015, from, http://www.alzheimersinnovation.com/pdf/Efficacy_of_a_Cognitive_Intervention_for_the_Therapeutic_Treatment_of_AD.pdf

Barnett, T., Walker, L. E., Jacob, E., Missen, K., Cross, M. D., & Shahwan-Akl, L. (2012). Expanding the clinical placement capacity of rural hospitals in Australia: Displacing Peta to place Paul? *Nurse Education Today*, *32*(5), 485–489.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101.

Brewer, M., Gribble, N., Robinson, P., Lloyd, A., & White, S. (2009). Assessment of interprofessional competencies for health professional students in fieldwork education placements. Paper presented to the ATN Assessment Conference, RMIT University, 19–20 November 2009.

Brewer, M. L., & Jones, S. (2013). An interprofessional practice capability framework focusing on safe, high-quality, client-centred health service. *Journal of Allied Health*, 42(2), 45–49.

D'amour, D., & Oandasan, I. (2005). Interprofessionality as the field of interprofessional practice and interprofessional education: An emerging concept. *Journal of Interprofessional Care*, 19(S1), 8–20.

Grealish, L., Lucas, N., Neill, J., McQuellin, C., Bacon, R., & Trede, F. (2013). Promoting student learning and increasing organizational capacity to host students in residential aged care: a mixed method research study. *Nurse Education Today*, *33*(7), 714–719.

Health Workforce Australia (HWA). (2011). National workforce innovation and reform strategic framework for action 2011–2015. Retrieved 11 Feb. 2015, from http://www.hwa.gov.au/sites/uploads/hwa-wir-strategic-framework-for-action-201110.pdf

Kirkpatrick, D. L. (1967). Evaluation of training. In R. Craig & L. Bittel (Eds.), *Training and development handbook* (pp. 87-112). New York: McGraw Hill.

Levett-Jones, T., Lathlean, J., McMillan, M., & Higgins, I. (2007). Belongingness: A montage of nursing students' stories of their clinical placement experiences. *Contemporary Nurse*, *24*(2), 162–174.

McNair, R., Stone, N., Sims, J., & Curtis, C. (2005). Australian evidence for interprofessional education contributing to effective teamwork preparation and interest in rural practice. *Journal of Interprofessional Care*, *19*(6), 579–594.

Neville, C. C., Yuginovich, T., & Boyes, J. (2008). A stocktake of existing aged care clinical placements for

undergraduate nursing students in Australia. *Australian Journal of Advanced Nursing*, 26(2), 17–26.

Productivity Commission. (2011). *Caring for older australians: Overview*, Report No. 53, Final Inquiry Report. Canberra: Author.

Reeves, S., Zwarenstein, M., Goldman, J., Barr, H., Freeth, D., Hammick, M., & Koppel, I. (2008). Interprofessional education: effects on professional practice and health care outcomes. *Cochrane Database Of Systematic Reviews*, 4.

Robinson, A., Abbey, J., Abbey, B., Toye, C., & Barnes, L. (2009). Getting off to a good start? A multi-site study of orienting student nurses during aged care clinical placements. *Nurse Education in Practice*, *9*(1), 53–60.

Robinson, A. L., Andrews-Hall, S., & Fassett, M. (2007). Living on the edge: Issues that undermine the capacity of residential aged care providers to support student nurses on clinical placement. *Australian Health Review*, *31*(3), 368–378.

Robinson, A., Abbey, J., Toye, C., Barnes, L., Abbey, B., Saunders, R., ... & Andre, K. (2006). *Modelling connections in aged care: Development of an evidence-based best practice model to facilitate quality clinical placements in aged care*. Report based on stages 1–3. Retrieved 11 Feb. 2015, from http://www.utas.edu.au/__data/assets/pdf_file/0008/375569/wdrec_txt_Modelling-report-1-3.pdf

Siggins Miller Consultants. (2012). Promoting quality in clinical placements: Literature review and national stakeholder consultation. Adelaide: Health Workforce Australia

World Health Organization (WHO). (2010). Framework for action on interprofessional education and collaborative practice. Geneva: Author.

Xiao, L., Paterson, J., Henderson, J., & Kelton, M. (2008). Gerontological education in undergraduate nursing programs: An Australian perspective. *Educational Gerontology: An International Journal*, 34, 763–81.

Brooke Sanderson is the Deputy Director of Practice and Interprofessional Education within the Faculty of Health Sciences at Curtin University in Perth. Jade Cartwright is a lecturer at the University of Melbourne, School of Health Sciences. Anne Whitworth is Associate Professor within the School of Psychology and Speech Pathology at Curtin University. Elizabeth Oliver is a senior occupational therapist at Catholic Homes Inc. Nigel Gribble is the Director of Fieldwork in the School of Occupational Therapy and Social Work at Curtin University.

Correspondence to:

Brooke Sanderson

Deputy Director Practice and Interprofessional Education Faculty of Health Sciences, Curtin University Kent Street, Bentley, Perth, WA, 6102 phone: (08) 9266 9124 email: b.sanderson@curtin.edu.au



A multidisciplinary approach to difficulty swallowing medication

An alternative to dose form modification

Emily Davis and Derek Kay

Difficulties swallowing tablets is an underrecognised and important issue that negatively impacts the health and well-being of many adult clients, and is not limited to individuals with dysphagia. Clients who experience difficulties may miss doses or resort to modifying medications in potentially dangerous ways to improve their ability to swallow them, such as crushing medications that should not be crushed. The cost of alternative liquid medications, where available, may be prohibitive. The purpose of this "Clinical insight" is to present a case in which assessing and addressing the swallowing difficulties of a single patient led to a service-wide switch to an alternative brand of medication that was easier to swallow. Changing the brand of tablets resulted in a "least modified" approach for this patient and an easier tablet to swallow for other patients. The case highlights that multidisciplinary care, including in this case input from a speech-language pathologist, is essential in optimising medication dosing.

ifficulties swallowing tablets is common in older people and people with dysphagia, but not limited to these populations (Schiele, Quinzler, Klimm, Pruszydlo, & Haefeli, 2013). Anyone may have difficulties swallowing medications, or find certain medications harder to swallow than others. People who experience difficulties may miss doses or attempt to alter the dose form (e.g., crush tablets) which may reduce medication effectiveness and result in harm (Marquis et al., 2013). Given the risks, speech pathologists have an important role to play as part of a multidisciplinary team in identifying and addressing these swallowing difficulties.

There is evidence to suggest that difficulties with swallowing medications may be underrecognised in health care settings. Schiele et al. (2013), for example, reported that 1 in 11 patients who attended their general medical practice had difficulties swallowing tablets or capsules, but 70.4% of the patients who reported difficulty swallowing tablets were not identified by their GP as having any

difficulty swallowing. Of the patients who reported that they had difficulties swallowing their tablets, 58.7% had modified their medication in a way that may have altered the effectiveness and safety of the medication. Notably, participants reported that the shape of the tablets they were prescribed affected how easy they were to swallow.

Assessing and addressing swallowing difficulties

In a hospital environment, a multidisciplinary team approach to ensure patients can swallow their medication is important. Typically, the speech-language pathologist (SLP) assesses the patient's swallowing ability and the pharmacist provides information on alternative or modified dose forms and compatibility with taking with thickened fluids. Nurses supervise the administration of medications and identify if patients are having difficulty swallowing and the medical team is responsible for writing or amending medication charts. This multidisciplinary team approach aims to facilitate compliance and reduce adverse drug events. Some key considerations and common strategies for addressing difficulties swallowing medications are presented below.

Modification of dose form may improve a person's ability to swallow medications safely. Dose form modifications and alternatives include:

- · cutting tablets in half
- crushing tablets
- opening capsules
- · giving whole or crushed medications with thick fluids
- · dispersing/dissolving the medication in liquid
- giving liquid formulations
- · thickening liquid formulations.

A pharmacist should be consulted to ensure that these modifications are not contraindicated, and to ensure the patient receives the least modified option. To illustrate, the modification of tablet dose forms may result in an "off licence" use if crushed. Some medications need to be swallowed whole with a glass of water to reduce oesophageal irritation (including alendronate and tetracycline antibiotics). People with dysphagia may be unable to do this. Other medications that must be taken on an empty stomach cannot be taken with thick fluids.

With regard to crushing, even when it is possible, this may result in an unpalatable taste, cause irritation, or result in an inconsistent dose being administered (Nunn & Williams, 2005). Cutting tablets, on the other hand, can result in sharp edges, and patients sometimes complain

DOSE FORM
DYSPHAGIA

MEDICATION PHARMACY

TABLET





Emily Davis (top) and Derek Kay

that cutting tablets results in "twice as many tablets to swallow". Some medications can improve swallowing by reducing excess saliva, or improving motor control, for example, in patients with Parkinson's disease. Other medications can impair swallowing by causing xerostomia, reflux, oesophagitis, or reducing muscle co-ordination (Gallagher and Naidoo, 2009).

Despite the challenges associated with administration, tablets are generally preferable to liquid formulations due to manufacturing, storage, dispensing, and cost advantages. Liquid medications tend to leave residue in the bottom of medicine cups, are often unstable, may have short expiration dates, are more difficult to measure, and typically cost more per dose. As many liquid medications are for the paediatric population, the volume required to swallow for an adult dose is often large (Singh, Philip, & Pathak, 2008). A usual adult dose of paracetamol (1000 mg four times per day) is almost 100mls of commercially available preparations per day. A person with dysphagia may have difficulty taking this volume of medication. Liquid paracetamol is almost 100 times more expensive per dose than tablets (approximately 8c per day for tablets, \$8 per day for liquid, and \$10 per day for intravenous administration).

In the community, many people with swallowing difficulties make their own dose form modifications by choosing brands that they find easier to swallow over others. However, in the hospital setting, the choice of brand may be limited by the hospital formulary. We present here a case which initiated a review of the brand of paracetamol stocked by the hospital and the benefits of this review for patients.

Case example

A patient admitted to the hospital for rehabilitation following a fracture was complaining of increasing difficulty swallowing. She was managing thin fluids and a soft diet, although she reported that her swallowing was "not as good as usual". Following this increased difficulty swallowing, she had an episode where a regular medication (paracetamol) "got stuck and burned her throat". She then had significant difficulty and pain on swallowing, and was acutely unwell. Her diet was modified to a minced diet, and she remained on thin fluids.

A pharmacy review was requested regarding crushing medications and liquid alternatives. She was commenced on liquid paracetamol to reduce pain, but declined doses stating that it caused stinging in her throat. A different brand of paracetamol tablet was trialled, which the patient was able to swallow with water without difficulty. This tablet was a different shape and texture. With other supportive care, and an improvement in ability to swallow food, fluids and medications, she improved over the following days and returned to her normal soft diet within a week.

In addition to providing advice on modified dose forms, the pharmacists identified that the patient was prescribed alendronate. Alendronate is a once weekly medication, and requires the patient to be able to swallow tablets whole with a glass of water on an empty stomach first thing in the morning and remain upright for 30 minutes following consumption. Alendronate is known to cause oesophageal irritation (de Groen et al., 1996). Difficulty swallowing the required amount of water, or the presence of reflux, would increase the risk of irritation from this medication, which may cause further difficulties swallowing. The patient had received her weekly dose two days prior

to the speech pathology assessment. Previous use of alendronate combined with swallowing difficulties may have resulted in or contributed to her initial oesophageal irritation, thereby increasing difficulties swallowing, which led to the paracetamol becoming "stuck". The medication was ceased following this episode. The pharmacist recommended the investigation of a non-oral osteoporosis medication.

Following the change in paracetamol tablet brand, liquid paracetamol use dropped by two-thirds across the medical and rehabilitation wards. Subjectively, there has been a reduction in referrals to SLP for "difficulty swallowing medications". Twelve months following the implementation of the alternative brand of paracetamol tablets, some staff and patients still comment on how difficult the tablets of the previous brand were to swallow. Changing the brand may have reduced the number of people having difficulties swallowing paracetamol, and the subsequent use and cost of liquid alternatives.

Discussion

As difficulties swallowing medications appear to increase with age, consideration of ability to swallow medication will become increasingly important with an ageing population. Although liquid forms may be available, in the case of paracetamol, they can be 100 times more expensive than tablets, and cannot be packed into dose administration aids (e.g., Webster packs). Older people may not have the dexterity to open a bottle with a child proof cap and accurately pour a dose of liquid medication. It was also highlighted in the article by Schiele et al. (2013) that in the community patients missed doses deliberately because medications were difficult to swallow.

Our case study highlights the fact that simple changes in practice can have important service-wide impact in addressing the needs of patients with swallowing difficulties. Paracetamol is a very common medication, particularly in the hospital environment, and is taken numerous times per day by many patients. In this case study, the simple action of changing brand and tablet shape had a significant impact for this individual. The change resulted in a less expensive, less modified, and more reliable dose for this medication. As a consequence of this trial the new brand of medication was rolled out across the hospital.

This case also highlights the importance of utilising a multidisciplinary approach to dysphagia management. An advantage of employing a multidisciplinary approach is that it encourages different approaches to solving a problem, which may result in more individualised, practical, and successful solutions for patients. In this instance, an alternative approach to addressing the patient's difficulty swallowing the paracetamol tablet may have been to substitute it with alternative oral, rectal, or intravenous dose forms. These may not be practical, acceptable, or cost effective for the patient involved. The changing of brand and therefore tablet presentation, through consultation with the pharmacy department, provided an acceptable, cost-effective, long-term solution for this patient which benefited many others.

Our experience suggests that prior to considering dose form modifications, it may be appropriate to consider if a different brand or coating improves a person's ability to swallow the medication. This approach may allow the person to receive the least modified form, potentially improving compliance with taking the medication, and reducing the cost burden to the patient or facility.

References

de Groen, P. C. Lubbe, D. F., Hirsch, L. J., Daifotis, A., Stephenson, W., Freedholm, D., & Wang, K. K., (1996). Esophagitis associated with the use of alendronate. *New England Journal of Medicine*, *335*(14), 1016–1021.

Gallagher, L., & Naidoo, P. (2009). Prescription drugs and their effects on swallowing. *Dysphagia*, 24(2), 159–66.

Gurwitz, J. H., Field, T. S., Harrold, L. R., & Rothschild, J. (2003). Incidence and preventability of adverse drug events among older persons in the ambulatory setting. *JAMA*, 289(9), 1107–1116.

Marquis, J., Schneider, M., Payot, V., Cordonier, A., Bugon, O., Hersberger, K.E., & Arnet, I. (2013). Swallowing difficulties with oral drugs among polypharmacy patients attending community pharmacies. *International Journal of Clinical Pharmacy*, *35*, 1130–1136.

Nunn, T., & Williams, J. (2005). Formulation of medicines for children. *British Journal of Clinical Pharmacology*, 59(6) 674–676.

Scheile, J. T., Quinzler, R., Klimm, H., Pruszydlo, M. G., & Hefeli, W. E. (2013). Difficulties swallowing solid oral dosage forms in a general practice population: Prevalence, causes, and relationship to dosage forms. *European Journal of Clinical Pharmacology*, 69, 937–948.

Singh, J., Philip, A.K., & Pathak, K. (2008). Optimization studies on design and evaluation of orodispersible pediatric formulation of indomethacin. *AAPS PharmSciTech* 9(1), 60–66.

Emily Davis is the manager of speech pathology at the Bathurst Health Service in New South Wales, and works primarily with acute and rehabilitation patients with swallowing and communication difficulties. **Derek Kay** is the director of pharmacy at the Bathurst Health Service.

Correspondence to:

Emily Davis

Bathurst Health Service email: emily.davis@health.nsw.gov.au

93

What's the evidence?

Montessori-based interventions for people with dementia in a residential aged-care setting

Jade Cartwright and Elizabeth Oliver

THIS ARTICLE HAS BEEN PEERREVIEWED





Jade Cartwright (top) and Elizabeth Oliver

here are currently over 322,000 Australians living with dementia, with that number projected to increase to 553,285 by 2030 (Access Economics, 2011; AIHW, 2015). Each week, there are more than 1,800 new cases of dementia diagnosed in Australia; equating to approximately one new diagnosis every six minutes (Alzheimer's Australia, 2015). Furthermore, more than 50% of people living in residential aged-care facilities have dementia, presenting with complex care needs (AIHW, 2012). Governments worldwide have recognised the need for concerted action (WHO, 2012), stimulating increased interest in new systems and care models with greater a focus on quality of care and the satisfaction and well-being of care recipients (ADI, 2013; Roberts, Morley, Walters, Malta, & Doyle, in press, 2015). The aged-care sector in Australia is undergoing significant reform, with a move towards consumer-directed care and wellness, reablement, and restorative services (Hornsey, 2015). While representing a positive step forward, access to therapeutic services for people with dementia remains limited and quality of care highly variable. This is despite a growing evidence base demonstrating the value of non-pharmacological interventions for people with dementia (Cabrera et al., in press, 2015; Cohen-Mansfield, Jensen, Resnick, & Norris, 2011; Cooper et al., 2012). This edition of "What's the evidence?" examines the evidence base for a specific non-pharmacological intervention, the Montessori approach, with particular attention to the role of speechlanguage pathology in supporting a service innovation.

Clinical scenario

You are a speech-language pathologist (SLP) working for an aged-care organisation committed to the provision of person-centred care. The senior occupational therapist has played an instrumental role in championing service innovation within the organisation, most recently advocating for the adoption of the Montessori approach by creating a dedicated memory support unit for 14 residents with dementia. You are familiar with the term "Montessori" as it applies to education; however have not previously experienced its application to dementia care.

Response to this scenario

You are open-minded and welcoming of the opportunity to be part of a new service innovation. You are acutely aware of the need to provide meaningful activities for people with dementia and enriching environments that promote engagement, personhood, and quality of life. This responds to research demonstrating that residents with dementia spend a large proportion of their day alone in passive

activities that can lead to boredom, loneliness, and the emergence of behaviours of concern, such as agitation and aggression, which can be problematic for family and staff (Beuttner, Lundegren, Lago, Farrell, & Smith, 1996; Ice, 2002; Moyle, McAllister, Venturato, & Adams, 2007). Furthermore, you are a strong advocate for non-pharmacological interventions, acknowledging that people with dementia retain the capacity and desire to learn, to participate and remain socially connected across all stages of the condition (Malone & Camp, 2007). To extend your knowledge you decide to appraise the evidence base for Montessori-based interventions for people with dementia.

Developing an answerable clinical question

To respond to this clinical scenario you first develop an answerable clinical question following the steps outlined in O'Holloran and Rose (2010). After considering the patient or problem, intervention, comparison intervention, and outcomes (see Table 1) you formulate the following clinical question: "What evidence is there for Montessori-based interventions for people with dementia living in residential aged care facilities?"

Searching for the evidence

You search a number of databases including Medline, PsychINFO, and ScienceDirect using the search terms listed in Table 1. You also search Google Scholar and the speechBITE™ database to ensure that all relevant records are identified. You search for the "patient or problem" and "intervention" keywords separately and then combine the results of each of these searches. You then review the

Table 1. Search terms		
PICO	Search terms	
Patient or problem	dementia aged care long term care	
Intervention	Montessori Montessori-based activities Montessori-based intervention Montessori programming	
Comparison intervention	No search terms – you are only interested in Montessori interventions	
Outcomes	No search terms – you are interested in any treatment outcome	

Authors	Overview	NHMRC level of evidence
Giroux et al. (2010)	Quasi-experimental design evaluated the short term effects of a Montessori approach for residents with cognitive impairments as compared to regular activities. Small, yet significant elevation in affect seen in the Montessori condition, with residents actively engaged for a greater proportion of time.	III-2
Jarrott et al. (2008)	Investigated effects of Montessori based activities delivered in small parallel groups (i.e., each resident uses own materials to complete tasks at own pace). Supports the provision of Montessori activities in a small group setting.	
Lee et al. (2007)	Randomised crossover design investigated effects of intergenerational Montessori-based programming on the engagement of residents with dementia. Higher levels of constructive engagement observed during intergenerational programming as compared to standard activities.	
Lin et al. (2011)	Randomised crossover design investigated the efficacy of applying a Montessori intervention to improve the eating ability and nutritional status of residents with dementia. The findings support a Montessori-based, early intervention protocol to assist residents with dementia to maintain self-feeding ability for as long as possible.	
Mahendra et al. (2006)	Systematic review and classification of the literature related to Montessori-based interventions for people with Alzheimer's disease. Class II and Class III evidence reported, supporting use of Montessori-based interventions.	
Roberts et al. (in press, 2015)	Pilot study evaluated a person-centred care model featuring Montessori-based activities. Demonstrated that organisation change is possible, with positive impact on residents' daily life and staff and family satisfaction.	
Skrajner & Camp (2007)	Investigated whether people with dementia can be trained to lead Montessori group activities. Demonstrated that training, simplified materials, and a controlled environment can enable people in the early to middle stages of dementia to lead Montessori group activities.	IV

Table 3. Critically appraised article			
Citation	van der Ploeg, E.S., Eppingstall, B., Camp, C.J., Runci, S.J., Taffe, J., & O'Connor, D.W. (2013). A randomized crossover trial to study the effect of personalized, one-to-one interaction using Montessori-based activities on agitation, affect, and engagement in nursing home residents with dementia. <i>International Psychogeriatrics</i> , 25(4), 565–575.		
Design	Randomised crossover trial		
Level of evidence	П		
Participants	44 people with dementia (29 severe, 13 moderate, and 2 mild dementia); average age 78.1 years. Participants were current residents of a dementia unit or specialist psychogeriatric nursing home.		
Experimental group	Personalised one-to-one activities delivered using Montessori principles were compared to a non-personalised activity (e.g., engaging in everyday conversation, looking at pictures in a newspaper).		
Results	Agitated behaviour counts reduced by 50% and 42% respectively in the Montessori and control conditions. The Montessori condition generated more positive affect and constructive engagement. The Montessori intervention was more effective in reducing agitation for participants who had lost fluency in English (all from non-English speaking backgrounds). Maintenance of effects during the 30 minutes directly after the interventions was limited.		
Clinical bottom line	Personalised activities are effective in eliciting more positive mood and constructive engagement for people with mild to severe dementia. Montessori interventions are especially suited for calming residents who have lost English language fluency.		

abstracts to identify publications relevant to the clinical question. Your initial search returns 32 articles, of which 18 are relevant to the topic. Of these, seven were directly related to the clinical scenario and selected for review. The National Health and Medical Research Council (NHMRC) intervention hierarchy (NHMRC, 2009) was used to determine the levels of evidence, listed in Table 2 along with an overview of each article. Table 3 provides a more

detailed critical appraisal of one article with the strongest research design.

The reviewed articles provide consistent evidence for the benefits of Montessori-based interventions for people with dementia. When compared to regular or routine activities (non-personalised), Montessori approaches were more effective in improving constructive engagement levels, associated with positive affect and signs of enjoyment

(Giroux et al., 2010; Mahendra et al., 2006; van der Ploeg et al., 2009). Furthermore, the Montessori approach enabled residents to adopt meaningful roles that reflect past interests and current abilities, allowing them to contribute and feel worthwhile (e.g., leading small group activities, delivering mail, gardening, setting the table).

Most of the appraised studies report findings of one-off projects investigating the efficacy of Montessori activities in comparison to routine or non-personalised activities. This is with the exception of Roberts et al. (in press, 2015), who successfully embedded Montessori principles into a new model of care that created a more homely and personcentred care environment and reduced antipsychotic and sedative prescription rates. This study provided qualitative evidence that Montessori-based interventions were well received by family members and allowed staff to feel better equipped to support residents to express their identity and provide opportunities for personal choice.

Future research should extend the current evidence base, with larger sample sizes and more robust randomised control trials required. This should compare the Montessori approach to other evidence-based interventions and systematically assess the ideal dosage and relative effects of Montessori principles. Many of the studies reviewed did not provide extensive demographic information regarding participants; however, the majority of trials appeared to involve participants with Alzheimer's disease. The application of a Montessori approach to other types of dementia, such as frontotemporal dementia and primary progressive aphasia, should be investigated. Interestingly, the reviewed studies did not assess the communication outcomes of Montessori-based interventions or collect any qualitative feedback directly from the participants with dementia themselves.

Clinical bottom line

After appraising the available literature you return to your clinical question and determine the clinical bottom line. There is Level II evidence for the efficacy of Montessoribased interventions for people with mild to severe dementia. As such, you are satisfied that a sufficient body of evidence supports the organisation's plans to implement a Montessori approach within the memory support unit. You feel confident that this could enhance provision of person-centred care and improve resident engagement, mood and behaviour; as well as the satisfaction of staff and family members. You discuss your findings with your occupational therapy colleague.

Speech-language pathologists can help facilitate Montessori-based interventions

Learning more about the application of Montessori principles to dementia care you identify a clear role for speech-language pathology. As a core principle of Montessori-based interventions, activities and roles must be tailored to an individual's interests and their current level of functioning (Malone & Camp, 2007). This requires comprehensive assessment of both cognitive and physical capabilities (Roberts et al., in press, 2015) and should include assessment of communication and language skills. As such, SLPs can help identify what activities and roles are suited to an individual resident based on communication capabilities (e.g., ability to join a reading group or read to other residents), as well as tailored cues, scaffolds, and environmental supports (e.g., accommodated instructions to support a resident with comprehension or hearing difficulties). Furthermore, Montessori principles can be embedded into communication or reminiscence groups (Jarrott et al., 2008); and many communication and swallowing-related tasks and functions can be trained using a Montessori approach (e.g., eating abilities such as

scooping food, lifting, or taking a bite; Lin et al., 2011). Given the prepared nature of Montessori activities and the increased focus on procedural (rather than verbal) aspects of a task, the approach is also well suited to clients with communication difficulties.

Montessori principles can be embedded into routine care delivery

A noted concern across the reviewed studies relates to the limited maintenance of engagement, behaviour, and mood effects immediately following completion of a Montessori activity. As such, you identify the importance of embedding Montessori principles into routine care delivery, rather than viewing the approach as a discrete or standalone intervention. Roberts et al. (in press, 2015) demonstrated that implementation at a service level is possible, enabled by strong leadership and use of Montessori champions, effective education and training strategies, and active engagement of key stakeholders in the planning, development, and implementation stages. Interestingly, ongoing support from an experienced dementia consultant was provided to staff throughout the 18-month trial, with "education outreach" representing a documented knowledge translation strategy (Power, 2014).

A wide range of people can be trained to facilitate Montessori-based interventions

The available evidence suggests that a wide range of people can be trained to facilitate Montessori activities, including family members, volunteers, and people with mild to moderate dementia. This is important for supporting the sustainability of the innovation and you identify potential to train SLP and occupational therapy students to deliver Montessori programs as part of scheduled clinical placements. Preliminary evidence also supports the delivery of Montessori-activities in small group settings, which may offer more feasible staff-to-client ratios and greater opportunity for socialisation between residents (Jarrott et al., 2008).

Resources are available to help translate Montessori principles into practice

In completing this review you were pleased to discover a range of resources that could assist dementia care teams to deliver Montessori-based interventions. There are articles that clearly describe and apply Montessori principles, providing illustrative case studies, examples of Montessori goals and session plans, and evidence-based practice guidelines (e.g., Mahendra et al., 2006; Malone & Camp, 2011; Orsulic-Jeras, Schneider, Camp, Nicholson, & Helbig, 2001). Gail Elliot's 2011 textbook is another useful resource that outlines theoretical principles as well as practical tools, forms and templates for translating Montessori Methods for DementiaTM into practice. Alzheimer's Australia Vic (2013) has also released a Montessori resource manual that is freely downloadable and provides a range of activity ideas for individual and group sessions.

Conclusion

Should your organisation consider implementing the Montessori approach for residents with dementia? In your view, there is satisfactory evidence to support use of Montessori-based interventions within the memory support unit, with potential for significant clinical impact. This would assist the organisation to meet accreditation standards, while demonstrating a direct response to current policy directives and care priorities promoting the provision of proactive, person-centred interventions and enabling

environments for residents with dementia. Furthermore, embedding Montessori principles into routine care delivery provides a significant opportunity to shift attitudes and combat stigma, demonstrating that people with dementia are capable of learning and must be provided with opportunities for engagement in meaningful roles and activities. Speech-language pathologists can play an important role in championing change and helping people with dementia reach their potential.

References

Access Economics. (2011). *Dementia across Australia:* 2011-2050. Report for Alzheimer's Australia. Sydney: Deloitte Access Economics Pty Ltd.

Alzheimer's Australia. (2015). Key facts and statistics 2015. Retrieved 2 Feb. 2015 from www.fightdementiaorg.au

Alzheimer's Australia Vic. (2013). *Relate, motivate, appreciate: A Montessori resource*. Retrieved 2 Feb. 2015 from https://fightdementia.org.au/sites/default/files/AlzheimersAustralia_Montessori_Resource_WEB.pdf

Alzheimer's Disease International (ADI). (2011). World Alzheimer Report 2011: The benefits of early diagnosis and intervention. London: Author.

Australian Institute of Health and Welfare (AIHW). (2015). Dementia in Australia. Canberra: Author.

Australian Institute of Health and Welfare (AIHW). (2012). Residential aged care in Australia 2010–11: A statistical overview. Aged care statistics series no. 36. Cat. No. AGE 68. Canberra: AIHW.

Buettner, L. L., Lundegren, H., Lago, D., Farrell, P., & Smith, R. (1996). Therapeutic recreation as an intervention for persons with dementia and agitation: An efficacy study. *American Journal of Alzheimer's Disease and Other Dementias*, 11(5), 4–12.

Cabrera, E., Sutcliffe, C., Verbeek, H., Saks, K., Soto-Martin, M., Meyer, G., ... Zabalegui, A. (in press, 2015). Non-pharmacological interventions as a best practice strategy in people with dementia living in nursing homes: A systematic review. *European Geriatric Medicine*, 6(2), 134–150.

Camp, C. J., & Lee, M. (2011). Montessori-based activities as a transgenerational interface for persons with dementia and preschool children. *Journal of Intergenerational Relationships*, 9, 366–373.

Cohen-Mansfield, J., Jensen, B., Resnick, B., & Norris, M. (2011). Knowledge of and attitudes toward non-pharmacological interventions for treatment of behavioural symptoms associated with dementia: A comparison of physicians, psychologists, and nurse practitioners. *The Gerontologist*, 52(1), 34–45.

Cooper, C., Mukadam, N., Katona, C., Constantine, G., Ames, D., Rabins, P., ... Livingston, G. (2012). Systematic review of the effectiveness of non-pharmacological interventions to improve quality of life of people with dementia. *International Psychogeriatrics*, 24(6), 856–870.

Elliot, G. (2011). *Montessori methods for dementia™:* Focusing on the person and the prepared environment. Moonah, Tas.: The Franklin Press.

Giroux, D., Robichaud, L., & Paradis, M. (2010). Using the Montessori approach for a clientele with cognitive impairments: A quasi-experimental study design. *International Journal of Aging and Human Development*, 71(1), 23–41.

Hornsey, C. (2015). Reablement: Ready or not? *Community Care Review*, 1, 20–21.

Ice, G. (2002). Daily life in a nursing home: Has it changed in 25 years? *Journal of Aging Studies*, 16, 345–359.

Jarrott, S. E., Gozali, T., & Gigliotti, C. M. (2008). Montessori programming for persons with dementia in the group setting: An analysis of engagement and affect. *Dementia*, 7(1), 109–125.

Lee, M. M., Camp, C. J., & Malone, M. L. (2007). Effects of intergenerational Montessori-based activities programming on engagement of nursing home residents with dementia. *Clinical Interventions in Aging*, 2(3), 477–483.

Lin, L. C., Huang, Y. J., Watson, R., Wu, S. C., & Lee, Y. C. (2011). Using a Montessori method to increase eating ability for institutionalised residents with dementia: A crossover design. *Journal of Clinical Nursing*, 20, 3092–3101.

Mahendra, N., Hopper, T., Bayles, K. A., Azuma, T., Cleary, S., & Kim, E. (2006). Evidence-based practice recommendations for working with individuals with dementia: Montessori-based interventions. *Journal of Medical Speech-Language Pathology*, 14(1), xv–xxv.

Malone, M. L., & Camp, C. J. (2007). Montessori-based dementia programming®: Providing tools for engagement. *Dementia*, 6, 150–156.

Moyle, W., McAllister, M., Venturato, L., & Adams, T. (2007). Quality of life and dementia: The voice of the person with dementia. *Dementia*, *6*(2), 175–191.

O'Halloran, R., & Rose, T. (2010). What's the evidence? Communicatively accessible healthcare environments. *ACQuiring Knowledge in Speech, Language and Hearing*, 12(3), 123–126.

Orsulic-Jeras, S., Schneider, N. M., Camp, C. J., Nicholson, P., & Helbig, M. (2001). Montessori-based dementia activities in long-term care: Training and implementation. *Activities, Adaptation & Aging*, *25*(3–4), 107–120.

Power, E. (2014). The effectiveness of knowledge transfer and exchange interventions for implementing rehabilitation evidence into clinical practice. *Journal of Clinical Practice in Speech-Language Pathology*, 16(1), 24–29.

Roberts, G., Morley, C., Walters, W., Malta, S., & Doyle, C. (in press, 2015). Caring for people with dementia in residential aged care: Successes with a composite personcentered care model featuring Montessori-based activities. *Geriatric Nursing*, 36(2), 106–110.

Skrajner, M. J., & Camp, C. J. (2007). Resident-assisted Montessori programming (RAMPTM): Use of a small group reading activity run by persons with dementia in adult day health care and long-term care settings. *American Journal of Alzheimer's Disease and Other Dementias*, 22(1), 27–36.

van der Ploeg, E. S., Eppingstall, B., Camp, C. J., Runci, S. J., Taffe, J., & O'Connor, D. W. (2013). A randomized crossover trial to study the effect of personalized, one-to-one interaction using Montessori-based activities on agitation, affect, and engagement in nursing home residents with Dementia. *International Psychogeriatrics*, 25(4), 565–575.

World Health Organization. (2012). *Dementia: A public health priority*. Geneva: Author.

Jade Cartwright is a lecturer at the University of Melbourne, School of Health Sciences. **Elizabeth Oliver** is a senior occupational therapist with Catholic Homes Inc.

Correspondence to:

Jade Cartwright

Lecturer

Department of Audiology & Speech Pathology The University of Melbourne 550 Swanston Street, Melbourne, VIC, 3010 E: jade.cartwright@unimelb.edu.au

A speech-language perspective on "doing good" in end-of-life care for people with advanced dementia

Helen Smith and Belinda Kenny

ADVANCED DEMENTIA
ETHICS
PALLIATIVE CARE





Helen Smith (top) and Belinda Kenny

Speech-language pathologists working with adults across the continuum of care from acute sub-acute hospitals to in home community services and nursing homes frequently encounter people diagnosed with dementia. Patients with dementia and their families often face challenging decisions about current and future management plans and goals of care. Speech pathologists must also address ethical challenges in providing care for such patients. This article discusses how speech-language pathologists may contribute to "doing good" to enable quality end-of-life care for people with advanced dementia through their communication and dysphagia expertise. Case studies illustrate the potential role of speech language pathologists in improving the quality of end-of-life care for people with advanced dementia.

oday, there are over 332,000 people diagnosed with dementia in Australia and 44 million people worldwide (Alzheimer's Australia, 2014). Indeed, a conservative estimate is that approximately 30% of Australians over the age of 85 have dementia (AlHW, 2012) and it is contended that Aboriginal and Torres Strait Islander people have higher rates of dementia and younger onset than other population groups in Australia (e.g., Li et al., 2014). Pneumonia, febrile illness, and dysphagia are frequently occurring challenges for people with advanced dementia in the last 6 months of life (Mitchell et al., 2009). Hence, speech-language pathologists (SLPs) have an important role in the assessment, treatment, and end-of-life management for people with advanced dementia.

People with dementia and their families often face challenging decisions about current and future management plans across a range of functional areas. Currently, dementia is the third leading cause of death in Australia (Alzheimer's Australia, 2014; Australian Bureau of Statistics [ABS], 2012). However, failure to recognise dementia as an incurable and progressive disease often results in inadequate end-of-life care (Coleman, 2012; Connor, Tecca, Lund-Person, & Teno, 2004; Torke, 2014;

Wolf-Klein, Pekmezaris, Chin, & Weiner, 2007). Importantly, many adults in the community express a preference for dying at home (Dekkers, Sandman, & Webb, 2002). Yet, a recent UK study found that 80% of adults with advanced dementia living in community dwellings and 30% of those living in residential care facilities did not die in their homes (Perrels et al., 2014). These findings highlight the need for greater awareness of issues associated with end-of-life care for adults with dementia.

End-of-life care is frequently managed by generalist health professionals and is not limited to palliative care "experts" (National Health and Hospitals Reform Commission, 2009). As frontline health professionals, SLPs may be involved in helping patients and their carers understand the predicted course of their dementia, particularly in the end stages. SLPs may experience ethical challenges when managing patients with dementia during end-of-life care. Here, we present two clinical scenarios drawn from the first author's professional experience and discuss the ethical issues at stake. The first case is an amalgamation of several cases from clinical practice. The second is used with permission from the patient's daughter. Pseudonyms are used to protect the identity of patients and their families.

Case 1: Antonio – Everything must be done to make dad better

Antonio was an 86-year-old Italian man with advanced dementia who presented to hospital with aspiration pneumonia, urinary tract infection, and delirium during his fourth admission for the year. Prior to admission, he was cared for at home by his daughter-in-law and son with assistance from his two daughters who lived in the same neighbourhood. Antonio had been unable to mobilise independently and had been dependent on his family for all activities of daily living (ADL) for several months, non-verbal for 6 months, and diagnosed with dysphagia for 12 months. SLP reassessment of his dysphagia indicated a severe swallowing impairment that deteriorated to profound dysphagia over the course of his admission.

Antonio's family requested full active measures with the goal for him to return home. Accordingly, Antonio was placed nil by mouth, treated with intravenous antibiotics, and three nasogastric feeding tubes were inserted (and pulled out by Antonio) in the first 10 days of admission. The treating medical team then ordered a percutaneous endoscopic gastrostomy tube (PEG) in response to the

family's request. The family expressed concerns not only about extending Antonio's life but also that he might be hungry.

Prior to the PEG placement, the treating SLP highlighted to the treating medical team the advanced nature of his disease and the risks associated with the PEG placement. The SLP raised the importance of discussing all options with the family, including palliation, which might include palliative oral intake for comfort/pleasure. The SLP also explained that it was typical for appetite to diminish at end of life. However, the medical team, inexperienced in palliative care, stated patients could live for "years" with dementia and the family wanted the PEG.

Antonio partially pulled out his PEG three days after it was inserted. His response to the PEG resulted in unintended negative consequences; chemical restraint, an infection in the PEG site, pain, and sepsis. Antonio had reportedly always loved food but his "active" treatment plan determined he was now unable to eat or drink. Antonio died 8 days later in hospital. His family expressed shock, distress, and anger at his death. This scenario will be recognised by many SLPs who work in the acute care setting. The nature and timing of Antonio's death was unexpected and unacceptable to his family.

Ethical dilemma

Antonio's case presents an ethical dilemma. The Speech Pathology Australia (SPA) Code of Ethics includes non-maleficence or "do no harm" as a fundamental principle (SPA, 2010). This means futile and burdensome treatment, such as aggressive antibiotic treatments (Givens, Jones, Shaffer, Kiely, & Mitchell, 2010) and PEGs, should be avoided in advanced dementia (Finucare & Bynum, 1996; Finucane, Christmas, & Travis, 1999; Mitchell, Kiely, & Lipsitz, 1997; van der Steen et al., 2014). Nonetheless, the SPA Code of Ethics (2010) states that SLPs must also seek to benefit others through our management. We argue that there are several factors that could have been addressed in Antonio's scenario to provide quality care, consistent with the ethical principle of beneficence.

Knowledge of advanced dementia

One issue concerns health professionals' knowledge of the process of death and dying. Medical technology has developed to such an extent that lay people, in this case

Antonio's loving family, and some health care professionals (particularly inexperienced staff members), are unable to tell when death is approaching (Dugdale, 2010). This lack of awareness of the terminal nature of advanced dementia is not limited to people living in the community. Often people in residential care facilities with advanced dementia are not perceived as having a terminal condition, despite the fact that approximately 70% die within 6 months of nursing home admission (Mitchell, Kiely, & Hamel, 2004).

The challenge for experienced SLPs is to assist lay people and inexperienced health professionals to recognise the signs of end of life in advanced dementia and assist people to prepare for the patient's dying and death, thus facilitating "doing good" in end-of-life care. Antonio's family may have perceived benefits and harms of the treatments offered quite differently if they had understood that he was dying.

According to Mitchell et al. (2009), all health professionals, when trying to prognosticate about death, would benefit from asking the simple question "Would you be surprised if Mr X died in the next 6 months?" Certainly, the SLP in this scenario reflected upon this question and answered a resounding "no." Antonio's age, in conjunction with his frail physical state, history of frequent hospital admissions, and diagnosis of advanced dementia made death a likely outcome in the next 6 months.

Communicating prognosis in advanced dementia

The clinical course of dementia is often described as "prolonged dwindling", with a long slow increase in frailty and decrease in functioning with high levels of disability in the last year of life (Gill, Gahbaur, Han, & Allore, 2010). The Speech Pathology Australia, Professional Competence, Standard of Practice (SPA, 2010) emphasises the need for SLPs to extend their professional knowledge to ensure competent practice. Knowledge of disease progression is essential for SLPs working with people with dementia. As presented in Table 1, there are well-described signs, particularly relevant to SLPs, which suggest the end stage of advanced dementia is approaching.

From an advanced dementia mortality perspective, Antonio's clinical prognosis was poor with limited mortality predicted even before the insertion and traumatic partial

Table 1. Mortality risk factors in advanced dementia		
Life Expectancy	Signs	
Days (i.e., death within 17–54 hours)	Extreme difficulty swallowing and a "death rattle" (Wilders & Menton, 2002; Wee & Hillier, 2008)	
3 months or less	Pain, restlessness, shortness of breath, difficulty swallowing, pneumonia and pressure ulcers (van der Steen, 2010; Givens, Jones, Shaffer, Keily, & Mitchell, 2010) Hypoactive delirium (Kapo, 2011)	
6 months or less	People with advanced dementia aged over 83, cardiovascular disease, diabetes mellitus, greater functional impairment, poor nutritional status, dyspnoea requiring oxygen, and not being awake most of the day (Mitchell et al., 2009) FAST stage 7c: Non-ambulatory, non-verbal with total dependence in all ADL (Mitchell et al., 2004b) The Advanced Dementia Prognostic Tool (ADEPT): Insufficient oral (Mitchell et al., 2010)	
12 months or less	Language limited to several words (Gill, Gahbauer, Han, & Allore, 2010) Dependent in all ADL (Gill, Gahbauer, Han, & Allore, 2010) 50% admitted to hospital with hip fractures or pneumonia (Kapo, 2011) Pneumonia, febrile episodes and eating problems (Mitchell et al., 2009) FAST stage 7: Language limited to several words and dependent in all ADL (Mitchell et al., 2004b)	

removal of the PEG tube and subsequent sepsis. From an ethics perspective, Antonio's family did not have access to accurate prognostic information that may have guided their decision-making during Antonio's death.

SLPs' contributions to high-quality palliative care

Palliative care can be an appropriate treatment approach for people such as Antonio. National Palliative Care week in 2014 had a theme of "Palliative Care Everyone's Business: Let's work together". This theme was consistent with a need for more knowledge and dialogue around palliative care among health professions and the community. Palliative care can be provided by primary care generalists with support from specialists (Commonwealth of Australia, 2009). A palliative approach to care is not restricted to the last weeks or days of life (Stirling et al., 2011; University of Queensland, 2012;). A SLP may therefore contribute to quality end-of-life care for people with dementia through both their communication and dysphagia expertise, particularly during the last years of life. SLPs may also be "present" with relatives and carers through the dementia journey, helping them to understand the subtle changes in function and symptoms as the dementia progresses. This professional role may contribute to better end-of-life care because distressing symptoms and burdensome interventions are less likely to occur when people with advanced dementia have health care proxies who understand the prognosis and clinical course of dementia (Mitchell et al., 2009). SLPs' knowledge that the end of life is associated with decreased hunger and thirst may help reassure families, such as Antonio's, that they are not "starving" him if his intake is inadequate, reduced, or limited.

Furthermore, SLPs' knowledge of the evidence around the limited benefits of artificial nutrition and hydration in long-term care settings (Australian and New Zealand Society for Geriatric Medicine, 2010; Daniel, Rhodes, Vitale & Shega, 2013; Kuo, Rhodes, Mitchell, Mor, & Teno, 2009; Monteleoni & Clark, 2004; Sharp & Shega, 2009) can contribute to carer and staff education. In the last days or weeks of life, SLPs may be advocates for comfort "palliative" oral intake and the positive patient benefits of decreased food and fluid intake. An Ethic of Care¹ approach would suggest including comfort feeding as ethically appropriate end-of-life care in advanced dementia such as Antonio's (Lopez, Amella, Strumpf, Teno, & Mitchell, 2010).

Communication in palliative care

SLPs are trained to interpret non-verbal behaviour and may identify vocalisations, grimacing, bracing, verbal complaints, and restlessness associated with pain for the team. SLPs' may also contribute to strategies, verbal and non-verbal, to diffuse anxiety and distress in adults with dementia and delirium (Alzheimer's Australia (WA), 2010). For a person who is non-verbal, such as Antonio, improved communication may have assisted in meeting comfort needs during his last days. SLPs' and other health professionals involved in the care of people with dementia and the counselling of their families have an ethical imperative to develop competence in discussing dying and death (Gamino & Ritter, 2012). Developing such competency may avoid a clinician's personal values, beliefs, or death anxiety interfering with their ability to be "present" with their clients.

Many health care workers in hospitals and residential care facilities may have limited skills in talking about dying

and death (Hennings, Froggatt, & Keady, 2010). To address this issue, some tertiary health professional preparation programs in Australia have integrated palliative care teaching as part of their curriculum (PCC4U, 2013). Guides for formally approaching end of life conversations have also been developed for health professionals (Stirling et al., 2011; University of Queensland et al., 2012). However, practice, supervision, and mentoring is required for SLPs' to develop competency in this fundamental area of practice. In the case of Antonio, if the health care team were more comfortable talking of death then the course of his dying may have involved less client and family suffering.

Antonio's scenario also raised issues regarding SLPs' role as client advocates in palliative care. Professional responsibilities include helping to educate family members to empower their decision-making. Perhaps the SLP in Antonio's scenario may have adopted a different or stronger approach to presenting evidence and questioning his management plan. By developing knowledge of Advanced Care Directives (SA Government, 2013) and the concepts of capacity and substitute decision-making, SLPs are more likely to be able to contribute effectively to the multidisciplinary team in supporting families and carers of people with dementia to make informed decisions. The importance of ethical and legal obligations surrounding doctors' rights to withhold futile medical treatment is frequently reinforced by experienced SLPs (Willmott, White, & Downie, 2013).

Cultural considerations

Issues of end-of-life nutrition and hydration are also infused with cultural conundrums. Many cultures see the provision of food and fluids as a fundamental act of care. For example, findings from a study in Singapore recommended increased use of nasogastric tube feeding at the end of life due to social, religious, and cultural factors to expressly prolong life of terminally ill people (Krishna, 2011). Cultural considerations may influence a family's desire for active treatment. The ethical principle of autonomy guides SLPs to respect clients' choices and may have been upheld in this scenario if Antonio's family expressed their preferences despite education regarding the options and potential outcomes affecting their father's care.

Case 1: Summary

Antonio's case illustrated how ethical practice underpins quality of care in advanced dementia. Benefits and harms must be clearly communicated to families with consideration given to the client's prognosis. Speech pathologists can make an important contribution to the care of people with advanced dementia. To this end, developing the skills to engage families in conversations about end-of-life care is essential for effective care. Antonio's case did not result in positive care outcomes for Antonio, his family, or the health care team. By contrast the following scenario, Molly's case, demonstrates how the outcome of a "good death" may be achieved for people with advanced dementia.

Case 2: Molly – A good death

Molly was an 85-year-old woman with advanced dementia living in a residential aged-care facility (RCF). Molly had been treated by a SLP some years earlier for tongue cancer. Her family continued to consult the SLP as Molly's communication and swallowing needs increased with her advancing dementia. Molly's daughter observed that Molly was becoming increasingly frail and less interested in eating

and drinking and asked the SLP what to expect at the next stage of her illness. The SLP then described typical changes in communication and swallowing and potential medical events such as dehydration and pneumonia associated with end-of-life dementia. The daughter, who was also a health professional, expressed gratitude for the SLP's honesty and support. Twelve months later Molly was totally bed bound, non-verbal and was eating and drinking very little of her modified diet and fluids or the water and ice she was offered. Her daughter received a call from the RCF informing her that Molly appeared to have pneumonia. She was asked if she wished Molly to be transferred to hospital. The daughter expressed a preference for a palliative approach in the RCF. The RCF was willing to provide this service and called a local GP to ensure Molly's comfort. The daughter called her siblings and 48 hours later Molly passed away peacefully in her home, with her children

Ethical issues

Molly and Antonio both died with advanced dementia. Both clients were supported by caring families and accessed health care services. Yet the outcomes of the two cases were markedly different. A key difference is the extent to which the ethical principle of autonomy (SPA, 2010) was upheld in both cases. In contrast to Antonio's case, Molly's family was prepared and made decisions regarding her care throughout the process of her dying. The SLP facilitated Molly's daughter's autonomous decision-making thereby focusing upon comfort and pain management. Hence, the SLPs approach was also consistent with ethical obligations to benefit Molly and her daughter by providing ongoing care. What were the features of this positive outcome for Molly?

The importance of the SLP relationship

In community and hospital environments, SLPs have an opportunity to develop professional relationships with people with dementia and their families and carers through a long and ongoing association such as the relationship between the SLP, Molly, and her daughter. With their skills in communication, SLPs may support families, such as Molly's, in their role as substitute decision-makers. Resources exist to support SLPs in this role (e.g., NSW Health, 2005; SPA, 2014). Health professional support and appropriate information for families and other substitute decision-makers has been shown to improve end-of-life care in advanced dementia. Support and information empowers families and health care teams to make informed choices and where appropriate use a palliative focus for care (van der Steen et al., 2014).

Speech pathology active involvement

Quality end-of-life care requires active involvement from all members of the interdisciplinary team, including SLPs. Once a patient has a documented palliative treatment plan (rather than an active curative treatment plan), SLPs may legally and ethically prescribe food and fluids that may be aspirated as the goal of treatment is now comfort and pleasure versus longevity (SA Govt, 2013). However, the SLP has ethical responsibilities to facilitate informed decision-making based upon clear communication regarding options, risks, and likely consequences of dysphagia management. Here, the ethical principle of autonomy is respected and the principles of beneficence and non-maleficence are argued by addressing psychosocial issues and prognosis.

Importantly, SLPs can take further active steps to benefit clients and reduce harm during palliative care. SLPs can help families and nursing/care staff understand the importance of good mouth care for a dying patient who is not eating and drinking. SLPs may also facilitate families and care staff to recognise non-verbal signs of pain and discomfort and to communicate through comforting touch and music (Alzheimer's Organisation, 2012). Molly presents a hopeful case study in a good death from advanced dementia. Her family was fully informed and able to be strong advocates throughout her life but particularly in the end stages. The RCF was willing and able to provide quality palliative care on site. The local GP was supportive and had capacity to provide informed palliative care. The treating SLP reflected that Molly had a good life and a good death.

Future directions

SLPs, similar to other members of the health care team, may have limited knowledge of advanced dementia and palliative care approaches. Consistent introduction of palliative care topics in entry-level SLP education programs in Australia may go some way to remediating this deficit. Appropriate clinical supervision and support are also required to define professional roles and facilitate skills in this complex and sometimes emotionally challenging area of practice.

Despite more than a decade of evidence around the futility of feeding tubes in advanced dementia, findings from a survey of American SLPs working in RCFs showed that more than 56% of respondents perceived a PEG would improve both nutrition and survival in people with advanced dementia (Sharp, & Shega, 2009). Many organisations employing SLPs lack organisational approaches such as policies and/or procedures around the prescription of feeding tubes or the use of palliative or comfort oral feeding for clients who are very elderly or diagnosed with advanced dementia. Absence of organisational policies can result in ad hoc management of these patients and ethical conflicts for team members. End-of-life management decisions, made in response to medical crisis, can lead to conflict between team members and/or the family/carers with regard to the goals of care for a person with advanced dementia. The timing of end-of-life discussions for RCF and home-based patients is critical if suffering at the end of life is to be diminished.

Oleg Chetnov, assistant director-general of the World Health Organization suggests "Whilst we strengthen efforts to reduce the burden of the biggest killers in the world today, we must also alleviate the suffering of those with progressive illness who do not respond to curative treatment" (World Wide Palliative Care Alliance, 2014, p. 3). Chetnov's statement issues a challenge to SLPs around the world who manage people with advanced dementia.

Conclusion

Advanced dementia and its management will demand increased attention by SLPs across the continuum of care as the incidence and burden of dementia increase. While much has been written in the last decade about prognosis and management at the end of life in advanced dementia, many people and their families face systems poorly equipped to provide quality end-of-life care. SLPs have professional perspectives informed by specialist knowledge, skills, and attitudes that may positively contribute to families' and carers' understanding of the end-of-life signs. SLPs may contribute toward decision-makers'

understanding of the risks and burdens, and positive attributes of interventions that may be offered to people with advanced dementia. By rising to the challenge of advanced dementia end-of-life management, SLPs may provide ethically sound practice and facilitate a good and peaceful death, free of suffering, for many people and their families.

Declaration

The authors report no conflict of interest. The authors alone are responsible for the content and writing of the paper.

Note

Ethic of Care is a philosophical approach to health care ethics. See SPA Ethics Education package (SPA, 2014) for further information.

References

Alzheimer's Australia. (2014). Dementia care in the acute hospital setting: Issues and strategies. Position Paper 40.

Alzheimer's Australia (WA) and Curtain University. (2010). Key elements of a palliative approach for people with severe and end stage dementia. Retrieved from http:// www.caresearch.com.au/caresearch/portals/0/documents/ whatispalliativecare/NationalProgram/PCDementiaCOP/A5-COP-booklet.pdf

Alzheimer's Organisation. (2012). Alzheimer's late-end stage care giving. Retrieved from http://www.org/care/ alzheimers-late-end-stage-caregiving

Australian Bureau of Statistics (ABS). (2012). Causes of death, Australia, 2010. ABS cat. no. 3303.0. Canberra: Author. Australian and New Zealand Society for Geriatric

Medicine. (2010). Dysphagia and aspiration in older people. Position Paper 12. Sydney: Author.

Australian Institute of Health and Welfare (AIHW). (2012). Dementia in Australia. Cat. no. AGE 70. Canberra: Author. Retrieved from http://www.aihw.gov.au/WorkArea/ DownloadAsset.aspx?id=10737422943

Commonwealth of Australia. (2009). A healthier future for all Australians: Final report of the national health and hospitals reform commission. Retrieved from http://www. health.gov.au/internet/nhhrc/publishing.nsf/content/1AFDE AF1FB76A1D8CA257600000B5BE2/\$File/Final_Report_of_ the%20nhhrc_June_2009.pdf

Coleman, A. M. E. (2012). End-of-life issues in caring for patients with dementia: the case for palliative care in management of terminal dementia. American Journal of Hospice and Palliative Medicine, 29(1), 9-12.

Connor, S., Tecca, M, Lund-Person, J., & Teno, J. (2004). Measuring hospice care: the National Hospice and Palliative Care Organization national hospice data set. Journal of Pain and Symptom Management, 28(4) 316-328.

Daniel, K., Rhodes, R., Vitale, C., & Shega, J. (2013). Feeding tubes in advanced dementia. Position statement. American Geriatrics Society. Retrieved from http://www. americangeriatrics.org/files/documents/feeding.tubes. advanced.dementia.pdf

Dekkers, W., Sandman, L., & Webb, P. (2002). Good death or good life as a goal of palliative care. In H. ten Have and D. Clark (Eds.), The ethics of palliative care: European perspectives (pp. 106-125). Buckingham, UK: Open University Press.

Dugdale, L. (2010). The art of dying well. Hastings Center Report, 40(6), 22-24.

Finucane, T. E., & Bynum, J. P. (1996). Use of tube feeding to prevent aspiration pneumonia. Lancet, 348(9038), 1421-1424.

Finucane, T. E., Christmas, C., & Travis, K. (1999). Tube feeding in patients with advanced dementia: A review of the evidence. Journal of the American Medical Association, 282(14), 1365-70.

Gamino, L. A., & Ritter, R. H., Jr. (2012). Death competence: An ethical imperative. Death Studies, 36, 23-40.

Gill, T. M., Gahbauer, E. A., Han, L., & Allore, H. G. (2010). Trajectories of disability in the last year of life. New England Journal of Medicine, 362(13), 1173-1180.

Givens, J. L., Jones, R. N., Shaffer, M. L., Kiely, D. K., & Mitchell, S. L. (2010). Survival and comfort after treatment of pneumonia in advanced dementia. Archives of Internal Medicine, 170(13), 1102-1107.

Hennings, J., Froggatt, K. & Keady, J. (2010). Approaching the end of life and dying with dementia in care homes: the accounts of family carers. Clinical Gerontology, 20, 114-117.

Kapo, J. M., (2011). Dementia. In L. Emanuel and S. Lawrence Librach (Eds.), Palliative care core skills and clinical competencies, (2nd ed.; pp. 464-470). Missouri: Elsevier. Retrieved from http://www.sciencedirect.com/ science/article/pii/B9781437716191001451

Krishna, L. (2011). Nasogastric feeding at the end of life: A virtue ethics approach. Nursing Ethics, 18(4), 485–494.

Kuo, S., Rhodes, R., Mitchell, S., Mor, V., & Teno, J. (2009). Natural history of feeding: tube use in nursing home residents with advanced dementia. Journal of the American Medical Directors Association, 10(4), 264-270.

Lopez, R. P., Amella, E. J., Strumpf, N. E., Teno, J. M., & Mitchell, S. L. (2010). The influence of nursing home culture on the use of feeding tubes. Archives of Internal Medicine 170(1), 83-88.

Li, S. Q., Guthridge, S. L., Aratchige, P. E., Lowe, M. P., Wang, Z., Zhao, Y., & Krause, V. (2014). Dementia prevalence and incidence among the Indigenous and non-Indigenous populations of the Northern Territory. Medical Journal of Australia, 200(8), 465-469.

Mitchell, S. L., Kiely, D. K., & Hamel, M. B. (2004a). Dying with advanced dementia in the nursing home. Archives of Internal Medicine, 164, 321-326.

Mitchell, S. L., Kiely, D. K., Hamel, M. B., Park, P. S., Morris, J. N., & Fries, B. E. (2004b). Estimating prognosis for nursing home residents with advanced dementia. Journal of the American Medical Association, 291(22), 2734-2740.

Mitchell, S. L., Kiely, D. K., Lipsitz, L. A. (1997). The risk factors and impact on survival of feeding tube placement in nursing home residents with severe cognitive impairment. Archives of Internal Medicine, 157(3), 327-332.

Mitchell, S. L., Miller, S. C., Teno, J. M., Kiely, D. K., Davis, R. B., & Shaffer, M. L. (2010). Prediction of 6-month survival of nursing home residents with advanced dementia using ADEPT vs hospice eligibility guidelines. Journal of the American Medical Association, 304(17), 1929-1935.

Mitchell, S. L., Teno, J. M., Kiely, D. K., Shaffer, M. L., Jones, R. N., Prigerson, H. G., ... Hamel, M. (2009). The clinical course of advanced dementia. New England Journal of Medicine, 361(16), 1529-1538.

Monteleoni, C., & Clark, E. (2004). Using rapid-cycle quality improvement methodology to reduce feeding tubes in patients with advanced dementia: Before and after study. British Medical Journal, 329, 491-494.

National Health and Hospitals Reform Commission. (2009). A healthier future for all Australians: Final report. Retrieved from http://www.health.gov.au/internet/nhhrc/ publishing.nsf/content/nhhrc-report

NSW Health. (2005). *Guidelines for end-of-life care and decision-making*. Retrieved from http://www0.health.nsw.gov.au/policies/gl/2005/pdf/GL2005_057.pdf

PCC4U. (2013). *Palliative care curriculum for undergraduates*. Retrieved from http://www.pcc4u.org/

Perrels, A. J., Fleming, J., Zhao, J., Barclay, S., Farquhar, M., Buiting, H. M., Brayne, C., & The Cambridge City over-75's Cohort (CC75C) study collaboration. (2014). Place of death and end-of-life transitions experienced by very old people with differing cognitive status: Retrospective analysis of a prospective population-based cohort aged 85 and over. *Palliative Medicine*, 28(3), 220–233.

Sharp, H.M., & Shega, J. W. (2009). Feeding tube placement in patients with advanced dementia: the beliefs and practice patterns of speech-language pathologists. *American Journal of Speech-Language Pathology*, 18(3), 222–230.

SA Government. (2013). Advanced Care Directives Act. Retrieved from http://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/about+us/legislation/advance+c

Speech Pathology Association of Australia (SPA). (2010). *Code of ethics*. Melbourne: Author.

Speech Pathology Association of Australia (SPA). (2014). Ethics education package. Melbourne: Author.

Stirling, C, Andrews, S., McInerney, F., Toye, C., Ashby, M., & Robinson, A. (2011). *Talking about dementia and dying: A discussion tool for aged care residential facility staff.* Hobart: Print Press.

The University of Queensland and Blue Care Practice Development Centre. (2012). *The palliative approach tool kit*. Retrieved from http://www.caresearch.com.au/caresearch/tabid/2840/Default.aspx

Torke, A. M., (2014). Building the evidence base for palliative care and dementia. *Palliative Medicine*, 28(3), 195–196

van der Steen, J. T. (2010). Dying with dementia: What we know after more than a decade of research. *Journal of Alzheimer's Disease*, 22, 37–55.

www.speechpathologyaustralia.org.au

van der Steen, J. T., Radbruch, L. Hertogh, C., Boer, M. E., Hughes, L., Larkin, P.,...Volicer, L. (2014). White paper defining optimal palliative care in older people with dementia: A Delphie study and recommendations from the European Association for Palliative Care. *Palliative Medicine*, 28(3), 197–209.

Wee, B., & Hillier, R. (2008). Interventions for noisy breathing in patients near to death. *Cochrane Database of Systematic Reviews* (1). Retrieved from Art. no.: CD005177. doi: 10.1002/14651858.CD005177.pub2

Wilders, H., & Menton, J. (2002). Death rattle prevalence, prevention and treatment. *Journal of pain and symptom management*, 23(4), 310–317.

Willmott, L., White, B. P., & Downie, J. (2013). Withholding and withdrawal of "futile" life-sustaining treatment: Unilateral medical decision making in Australia and New Zealand. *Journal of Law and Medicine*, 20(4), 907–924.

Wolf-Klein, G., Pekmezaris, R., Chin, L., & Weiner, J. (2007). Conceptualizing Alzheimer's disease as a terminal medical illness. *American Journal of Hospice and Palliative Medicine*, *24*(1), 77–82.

World Wide Palliative Care Alliance. (2014) Global atlas of palliative care at the end of life. Retrieved from http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf

Helen Smith is manager, Speech Pathology Department, The Queen Elizabeth Hospital (CALHN) and has been a member of the Speech Pathology Australia Ethics Board since 2008. **Dr Belinda Kenny** is a Research Fellow, the University of Sydney, and has been a member of the Speech Pathology Australia Ethics Board since 2010.

Correspondence to:

Helen Smith

Manager, Speech Pathology Department The Queen Elizabeth Hospital 28 Woodville Rd, Woodville South SA

phone: (08) 8222 7618

email: Helen.smith4@health.sa.gov.au



Around the journals

Gaynor, E., Geoghegan, S., & O'Neill, D. (2014). **Ageism in stroke rehabilitation studies.** *Age and Ageing*, *43*, 429–431. doi: 10.1093/ageing/afu026

Deborah Hersh

The authors of this article highlight previous research studies that have revealed evidence of ageism both in the clinical management of stroke and in a range of intervention studies of stroke. Their focus in this article was to review whether this is also the case with rehabilitation studies: "it is not clear to what extent the populations of participants in these studies mirror the age profile of patients encountered in clinical practice" (p. 429). In the United Kingdom and Ireland, the average age of stroke is 75 years.

Using the Cochrane Database of Systematic Reviews, the authors evaluated 23 reviews under the search term "stroke rehabilitation" published between 2003 and 2013. These reviews included information on 182 RCTs published between 1980 and 2012. The average age of patients across these trials was 64.3 years (57.2% male and 42.8% female), about 10 years younger than the average age seen in clinical practice. Of the 149 of those trials, which specified exclusion criteria, 46% excluded patients with significant cognitive impairment and 23% excluded patients with a documented aphasia. The authors suggested that these findings make the application of study results to clinical populations less reliable than they might be: "it is important that this more vulnerable cohort of patients is represented adequately in trials, not only because they reflect an appreciable proportion of patients suffering from stroke internationally but also to ensure that the development of evidence-based rehabilitation methods is both appropriate and applicable to this age group". They also note the increased prevalence of cognitive and communication impairments in older and more frail groups of patients and call for researchers to find ways to include these patients in trial designs by attending to complex consent and assessment processes.

Gellie, A., Mills, A., Levinson, M., Stephenson, G., & Flynn, E. (2015). **Death: a foe to be conquered? Questioning the paradigm.** *Age and Aging*, *44*, 7–10. doi: 10.1093/ageing/afu116

Helen Smith

One hundred years ago, 90 per cent of people died at home. Today, 65 per cent of people die in hospital. The main causes of death are cardiovascular disease and cancer. Dementia is the fourth major "killer" (Cummings, 2011). World-wide, only one in ten people who require palliative care receive it (WHO, 2014). In our modern society, death even in old age is often viewed in skewed

This commentary challenges the reader, particularly those from developed countries, to recognise death as a natural end of life. It contends that the modern language

of death portrays the death as a "foe to be conquered", a "battle". In contrast, the authors suggest that dying is an inevitable part of life, particularly for older people with chronic and progressive diseases. Furthermore, the authors ask the reader to consider that preparing for death through discussion and advanced care planning may have its own value and meaning for patients and their families.

The prevailing modern ideology of "death as foe" is questioned through the use of a case example. The case, taken from a newspaper article, is all too familiar for health professionals. An elderly man in his 80s with significant, multiple co-morbidities including two types of cancer, a stroke, and renal failure presents to hospital. The man's wish is to die rather than be treated for further deterioration. Both the medical team and extended family ignore this wish. Ignoring the patient's desire to "die rather than go to a nursing home", he is subjected to relentless and burdensome treatment. Ultimately, he is placed in a nursing home contrary to his expressed wish.

The commentary reflects on how situations such as those described in the case arise. The authors examine the origins of the perceptions of death as "unexpected and unwarranted", even in the frail elderly in both our hospitals and society. Using a historical, sociological, and cultural approach, the authors explore the role of everexpanding medical knowledge and technology in changing the communities' perception of the naturalness of death, leading to the expectation that medically, there is always more that can be done. The authors describe the loss of common personal experiences of death and dying particularly in the last hundred years, highlighting that for many, intimate experiences of death are rare before middle age. The authors illustrate how media, television, and films frequently portray death as premature, sudden, and violent.

All these factors may contribute to the lack of recognition by patients, families, and even medical professionals of the "common death" and dying. This lack of recognition of death may result in unwanted, futile, or burdensome treatments being provided. In contrast, awareness and acceptance of death and dying, particularly for older members of our community, may facilitate the provision of good, coordinated, palliative care. The authors contend that a natural and realistic view of death may contribute to patient comfort and provide the opportunity for more people to complete their lives in a peaceful, dignified and meaningful way.

Hallé, M., Le Dorze, G., & Mingant, A. (2014). **Speech-language therapists' process of including significant others in aphasia rehabilitation.**International Journal of Language and Communication

Disorders, 49(6), 748–760. doi: 10.1111/1460-6984.12108

Josephine Kemp

A variety of interventions designed to include family members and friends of people with aphasia in aphasia rehabilitation have been developed in recent years, including communication partner training and educational programs about aphasia. These interventions have documented positive effects on significant others' psychosocial well-being and ability to support the communication and participation of people with aphasia, and it is recommended that rehabilitation includes the significant others of people with aphasia. However, the extent to which these interventions form part of speechlanguage therapists' (SLTs) current clinical practice is unknown.

The aim of this qualitative study was to explore the process through which SLTs work with significant others of people with aphasia in rehabilitation settings.

Participants were eight SLTs who had been working with people with aphasia in one of four inpatient and outpatient rehabilitation facilities for at least 1 year. Participants were female, aged between 27 and 53 years with a mean age of 40, and had worked with people with aphasia for between 4 and 31 years with a mean of 15 years. The SLTs participated in individual semi-structured interviews, and grounded theory principles were applied in analysing the interview transcripts.

A model was developed theorising SLTs' process of working with significant others of people with aphasia in a rehabilitation setting. Central to this process was participants' perception that working with significant others was challenging, although a bonus to their fundamental patient-centred approach. Clinical experience and workplace environment influenced the development of this perception. With experience, SLTs reported becoming open to including significant others in rehabilitation, but noted several challenges to including them, including their accessibility. When significant others were available, basic interventions were undertaken to include them, such as inviting significant others to therapy and information sharing. Participants rarely provided significant others with language exercises or trained them to communicate more effectively with the aphasic person. Participants indicated they had unachieved ideals, including more frequent contact with significant others, even if they felt satisfied with their efforts to offer interventions to the family members and friends of people with aphasia.

The authors advocate re-evaluation of SLTs' perceptions of including significant others in aphasia rehabilitation. They suggest if SLTs perceive including significant others as a feasible necessity, rather than as a challenging bonus, they will be more inclined to include significant others in aphasia rehabilitation, with the aim to improve their communication with the person with aphasia. Suggestions to promote this re-evaluation include featuring in-depth training about family intervention in the SLT curriculum, redefining the concept of patient, and exploring SLTs' beliefs and emotions related to including significant others in aphasia therapy.

www.speechpathologyaustralia.org.au JCPSLP Volume 17, Number 2 2015 105



Webwords 52

Speech-language pathology: A young profession in an ageing world

Caroline Bowen



In 35 years' time, anyone who remembers Webwords may pause for a bit on 4 December to think about the 105th anniversary of her birth. Unlike **Clint Eastwood**', Webwords doesn't want to be 105. She is comfortably adjusted to the idea that she will not be available to say "Happy Birthday" to you, or to see what the fashionable septuagenarian SLP/SLT is wearing: when you, dear reader, will be...how old²? Putting it another way, when 2050 ticks around, will you be among the projected 22.7% of Australians aged 65 years or more, or the 5.1% over 85? And, if this is important to you, might you still be working between 65 and 85 and beyond?

If **Susan Ryan**³, Australia's inaugural Age Discrimination Commissioner's plans pan out, you could well be. Dr Dr Dr Ryan (who has not one, not two, but *three* honorary doctorates) bemoans the current situation in which millions of older Australians are locked out of the workforce by age discrimination, and the consequent waste of human capital. The commission she heads is bent on changes that will see laws and policies reformed to ensure that people's decision to **work past their 60s**⁴ is safe and uncontroversial.

Such flexibility would have been unthinkable in most work settings 35 years ago, the year that Azaria Chamberlain was killed by a dingo at Uluru, Candice Reed 12 days her senior and Australia's first "test tube baby" was born, Malcolm Fraser was prime minister, Zelman Cowan governor general and Mary Buttifant **President of our Association**⁵. As well in 1980, Channel 9 launched the quiz show *Sale of the Century*, the Great Barrier Reef was given World Heritage listing, and Webwords had been an SLP for a decade, in an era when speech pathology was still a nice thing for a nice girl to do. Not many men adorned the profession in those days. We used to talk about it.

Some things change, some stay the same

Not many men adorn the profession these days. We talk about it still. Men comprise 3% of the 2015 Speech Pathology Australia (SPA) member base of 4,178 women and 142 men who together represents 80% of the overall SLP workforce in Australia. On 2 February 2015, Marni Bradley, SPA's Manager of Member Services and Operations, kindly emailed Webwords the figures displayed in Table 1. They were drawn from this year's membership renewals and new memberships to date. Moments later, another email from the association came with the welcome

announcement of Dr Jade Cartwright as the 2016 National Tour Speaker, presenting two-day workshops on "Speech Pathology Services for People Living with Dementia across the Continuum of Care".

Table 1. Selected SPA new, renewing and student member characteristics, 2 Feb. 2015					
	, 0	Male SPA members (excluding students) by age N = 142		Student SPA members only N = 123	
Age	Proportion	Age	Proportion	Gender	Total
22–34	45.14%	24–34	55%	Female	118
44–35	26.51%	35–44	47%	Male	5
54–45	17.17%	45–54	22%		
64–55	9.45%	55–64	14%		
>65	1.73%	>65	4%		
Source: http://www.speech-language-therapy.com/images/					

Source: http://www.speech-language-therapy.com/images/spastats2feb2015.png

This timely news prompted Webwords to wonder how many SPA members worked with older people. It turned out that on their joining or renewal forms 1,949 members said they worked with adults (18–65), 870 worked with "the aged" (over 65), and 1,991 worked with both populations (18–65 and >65). If that means that 2,861 SPA members work with over-65s, 93.89% of them are missing out on helpful discussions in SPA's **Ageing and Aged Care Member Community**⁶ on Facebook, with its membership of just 175. The Trusty Webwords Crystal Ball (TWCB) confidently predicts that the 2016 National Tour will attract better numbers than *that*!

At present, the Australian speech pathology workforce consisting of SPA members (80%) and non-members (20%), has a young age profile, with fewer than 10% aged 55 years and over (HWA, 2014). Australian Bureau of Statistics (ABS, 2012) comparison data between self-reports by members of medical and allied health professions show that SLPs are in the lowest median age group (30–34 years), have one of the lowest percentages of people aged 55 years and over (6.8%) and the highest percentage of employed females (97.5%).

HelpAge International

Whatever your age, and wherever you are, it will not have escaped you that we live in an ageing world and that population ageing is altering economies and societies worldwide. But did you know that by 2050 nearly one in five people in developing countries would be over 60? As a global movement for the rights of elders, HelpAge **International**⁷ helps older people assert their rights, counter intolerance and overcome poverty so that they can enjoy dignified, safe, dynamic and healthy lives. In conjunction with more than 100 affiliates, the organisation works in Africa, the Caribbean, East Asia, Eastern Europe and Central Asia, Latin America, the Occupied Palestinian Territories and South Asia. It lists among its 2014 achievements having reached 1.5 million vulnerable old folk and their families, improved pension schemes in 14 countries and supported 250,000 older people in accessing health services.

What do you mean, "older"?

HelpAge International's photo gallery and stories, the Twitter accounts it **follows**⁸, the World Health Organization's **Ageing and Life-course**⁹ program, and *The Lancet*'s series of six **papers on ageing**¹⁰ reveal that the concept of codger, crumbly, elder, geriatric, old-buffer-old-dear-old-dog-old-fossil-old-soul-old-timer, **older or elderly person**¹¹, senior citizen or war-horse varies greatly. Some individuals count themselves "old" in their 50s and 60s; some agencies such as National Seniors Australia serve people 50 and over; while our federal government's Home and Community Care services are available to eligible citizens 65 years or older, or 50 years or older to Indigenous Australians who qualify.

APA mythbuster

Does the expression "older Australian" imply a 50- to 65-vear-old? While it obviously does for some, in 2007 the Australian Psychological Society (APS) surveyed 1.500 people, finding that 52% of 18- to 40-year-old respondents believed a person is not "aged" until their 70s, while 55% of respondents aged 61 years or more viewed people as "aged" once they were in their 80s. Amanda Gordon, APS president at the time, commented optimistically, "Rather than the common myth of a dreary old age, the majority of Australians are looking forward to older age and retirement, with benefits including freedom, an active social life and spending more time with family." Analysis of the responses from older Australians showed common difficulties, for which the APS offers easy-to-follow advice¹² about $\mbox{ageing positively}\xspace^{13},$ were around: maintaining health and fitness; maintaining social networks and activities; experiencing feelings of sadness and loss; ensuring financial security; dealing with decreases in mobility and an increased reliance on others.

A-to-Z of ageing

Word-game loving SLPs/SLTs with time to fritter could quickly generate an unhappy A-to-Z of ageing from **Alzheimer's**¹⁴ to Zimmer Frames; or a happy one from Anniversaries (more of those than you can poke a memory stick at, with luck) to **Zest for life**¹⁵. But it struck Webwords that it is all about As and Ds among many of the older people we engage with, personally and professionally.

The Ageing As can be: an older person's inspiring Attitude: their Acceptance and Appreciation of getting on – and getting on with it; their Affirmation of life despite its vicissitudes; their Adaptation to a loss such as retirement from the paid workforce or a bereavement; their Accommodation and Adjustment to changes in location and lifestyle. Aspirational As for the community at large might include more general Acknowledgement of older Australians' contributions to society, for example, as informal carers and volunteers. The not-sopositive As might include Alzheimer's, Aphasia, Arthritis, Atherosclerosis, patronising "Ah, blesses" 16 and the like. The positive Ds (Decisiveness, Determination, Durability) are a little difficult to pin down, but Dentistry and Dentures to one side, the disheartening ones - only one of which is inevitable - include the recurrent Dad-joke recounted several times daily, Dementia, the **Desperation**¹⁷ of family members and carers¹⁸ of people who are dementing, Dysphagia, Deafness, Depression and Death¹⁹.

Working with people

Speech Pathology Australia is the lead organisation to inform and advance the directions speech pathology takes in this country. Its current and well-considered **Strategic Plan**²⁰ reveals the vision, values and key objectives for the organisation for 2014–16. In it, aged care shares centre stage, along with speech pathologists in schools, disability, and juvenile justice, within its overarching lobbying plan and annual business plans. The Strategic Plan emphasises the importance of "working with" instead of "working on behalf of" people of all ages with communication and swallowing disorders.

It is impossible to predict *exactly* how the profession will deal with its changing roles as the demand for services for older people increases. Will the pattern of female dominance, and workforce attrition from full-time to part-time work after 10 years of service (HWA, 2014) persist? Will the profession stay "young"? Will someone find a magical way of ensuring adequate services in rural, regional, and remote Australia or to make waiting lists for services a thing of the past? What will our fabulous profession look like 35 years from now? Will it be exemplary? Will it be raining men?



Source: http://www.speech-language-therapy.com/images/crystal.jpg

Even the TWCB is silent on these matters so Webwords cannot say. But what she will say is, Happy Birthday for 2050!

References

Australian Bureau of Statistics (ABS). (2012). *Census of population and housing, 1996 to 2011*. Canberra: Commonwealth of Australia.

Health Workforce Australia (HWA). (2014). Australia's Health Workforce Series: Speech pathology in focus. Retrieved 5 Feb 2015 from http://www.hwa.gov.au/sites/default/files/HWA_Speech_Pathologists_in_Focus_V1.pdf

Links

- 1. http://abc7.com/archive/9082634
- 2. http://www.calculator.net/age-calculator.html
- https://www.humanrights.gov.au/about/commissioners/ age-and-disability-discrimination-commissioner-honsusan-ryan-ao
- https://www.humanrights.gov.au/publications/workingpast-our-60s-reforming-laws-and-policies-2012
- http://www.speechpathologyaustralia.org.au/aboutspa/council/past-councils
- 6. https://www.facebook.com/groups/ SPAAgeingAgedCare
- 7. http://www.helpage.org
- 8. https://twitter.com/helpage/following
- 9. http://www.who.int/ageing/en
- 10. http://www.thelancet.com/series/ageing
- 11. http://www.who.int/healthinfo/survey/ageingdefnolder/en/
- 12. http://www.psychology.org.au/publications/tip_sheets/ageing/

- http://www.psychology.org.au/publications/tip_sheets/ ageing
- http://www.smh.com.au/good-weekend/nationaltreasure-anne-deveson-faces-up-to-alzheimersdiagnosis-20150130-12mpwo.html
- 15. https://au.lifestyle.yahoo.com/prevention/a/16314686/ dr-rosemary-stanton
- http://www.lrb.co.uk/v36/n09/jenny-diski/however-ismell
- 17. http://www.mamamia.com.au/wellbeing/mother-hasalzheimers
- 18. http://www.thesocialcareelf.net/populations-andsettings/family-carers/terrible-maze-dementia-carersexperiences-health-social-care
- 19. https://www.youtube.com/watch?v=1mRec3VbH3w
- http://www.speechpathologyaustralia.org.au/library/ Core_Assoc_Doc/6136_SPA_Strategic%20Plan_ OUT2_LR.pdf

Webwords 52 is at www.speech-language-therapy.com with live links to featured and additional resources.

Speech pathology resources

Morgan-Jones, P., Colombage, E., McIntosh, D., & Ellis, P. (2014). *Don't give me eggs that bounce: 118 cracking recipes for people with Alzheimer's*. Sydney: HammondCare MediaAustralia. ISBN: 9780987189295, pp. 252; RRP: \$39.95.

Caroline Baker

Speech pathologists and dietitians are well placed to advocate for individuals who require clinically safe and nutritionally adequate meals that don't compromise on taste and appeal. Don't give me eggs that bounce: 118 cracking recipes for people with Alzheimer's is a useful and informative resource for use in the home, hospital, or



other settings including aged care. It is much more than another Australian recipe book. It offers a catalyst for change in meals for people with dysphagia. It inspires greater focus on upholding a person's dignity and positive dining experiences, particularly in aged care. Leading aged care chef Peter Morgan-Jones has joined with health professionals including Prudence Ellis, a speech pathologist, to produce a resource specifically for people with dementia. However, there is suggestion that it may help a variety of people including older adults and people with "eating disabilities".

There is a proud endorsement by cook and TV presenter Maggie Beer who has boosted awareness of this complex issue in the community. Immediately upon perusal, one is drawn to the sumptuous food photography that inspires cooking! The format of text and font is attractive and the use of "plain language" with medical terms explained makes the book easy to read. Background regarding how the book came to be and "a few words about dementia" are provided. Practical information then follows about nutrition and successful eating in dementia, swallowing, preparing and plating texture-modified foods, and caring for the carer. The healthy recipes are divided into breakfast, lunch, dinner, mid meals, dessert, and beverages (including thickened). In addition, there are recipes sectioned under "soft", "minced and moist", and "smooth pureed". Importantly, each recipe has a symbol guide which indicates the texture-modified food or fluids for which the recipe is suitable. For example,

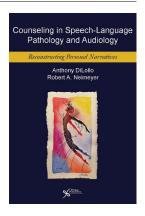
the texture-modified range runs from "R" for regular diet, no restriction, through to "SP" for smooth pureed. Fluid symbols vary from "T" for thin fluids, no restrictions, through to "Th3" for extremely thick fluids. The book is rounded off with information about meal plan ideas, contacts and resources, helpful kitchen equipment, detailed nutritional information, and conversions. The author of this review "road tested" the scones and a lemon ricotta cake – both delicious!

In terms of clinical use, it would be handy to have a copy to show clients and direct them to useful sections and where-to-buy details. It could also be used as a resource to "show and share" at dysphagia staff training sessions and/or food service meetings within hospitals. The authors encourage us to keep the conversation going by visiting www.crackingrecipes.com.

DiLollo, A., & Neimeyer, R. A. (2014). Counseling in speech-language pathology and audiology: Reconstructing personal narratives. San Diego, CA: Plural Publishing, Inc. ISBN: 978-1-59756-484-7; pp. 368; US\$49.95; www.pluralpublishing.com

Ashleigh Pascoe

Speech pathologists play an integral role in counselling communication and swallowing disorders, as documented in Speech Pathology Australia's Scope of Practice (The Speech Pathology Association of Australia, 2003). Although counselling is highlighted as an important skill in the speech pathologist's repertoire, understanding the concept of counselling and



how this can be applied to clinical practice can be challenging.

Counseling in Speech-Language Pathology and Audiology by DiLollo and Neimeyer (2014) is an invaluable resource for experienced clinicians, new graduates and students in the field of speech pathology and audiology. This book takes readers on a journey, aiming to empowerthem to challenge their thinking and understanding of counselling, focusing on a constructivist-

narrative perspective. This approach focuses on "the client as the expert and each client's personal narrative" (DiLollo & Neimeyer, 2014, p. viii) – a fitting framework for speech pathologists.

The authors of this book have many years of clinical and research experience (DiLollo is a qualified speech pathologist originating from Perth). The book is arranged into five parts, together consisting of 26 chapters. Part I aims to orientate readers to the idea of counselling, while addressing common myths in regards to counselling in clinical practice. Part II provides information on theoretical frameworks of counselling, while Part III details the process of counselling. In Part III, a chapter is dedicated to understanding the constructivist-narrative approach, and includes a summary of key points (a nice touch to ensure thorough understanding). Part IV is termed "Clinician's Toolbox" and contains chapters on creative tools to assist counselling interactions, such as: drawing, self-characterisation and play therapy, to name a few. The final

part of this book (Part V) is dedicated to the teaching of the constructivist counselling framework.

The structure of this book makes it engaging and user-friendly. An outline is provided at the beginning of each part to highlight what the proceeding chapters are about, as well as conclusions at the end of each chapter. The use of case studies, transcripts of counselling sessions and "toolbox" information ensures an enjoyable, informative and clinically valuable read. The case studies and transcripts help to demonstrate how theory translates into practice, which students could find particularly useful. The passion of both authors for this topic is evident through their engaging, descriptive writing style.

References

DiLollo, A., & Neimeyer, R.A. (2014). *Counseling in speech-language pathology and audiology: Reconstructing personal narratives.* San Diego, CA: Plural Publishing, Inc.

The Speech Pathology Association of Australia. (2003). Scope of practice in speech pathology. Melbourne: Author.

Would you like to contact more than 6,000 speech pathologists?



Advertising in *JCPSLP* and *Speak Out* is a great way to spread your message to speech pathologists in Australia and overseas. We have different size advertising space available.

If you book in every issue for the whole year you'll receive a discount.

See www.speechpathologyaustralia.org.au for further information about advertising.



Top ten resources in aged care

Jill Lesic

r Jill Lesic & Associates Speech Pathology is a national speech pathology company providing speech pathology services to individuals in their homes and residential care facilities. The speech pathologists who contributed to this article were: Dr Jill Lesic, Meredith Potts, Madeleine Dziubek, Laura Del Medico, Lauren Woodbridge, Jane Villari, Sonia Pang, Jody O'Connor, Kate McCullough, Dailan Evans, Jessica Linke, Fiona Marzo, Carla Fraser, Daphna Eshel, and Kristie Constance

1 Dysarthria and dysphagia manuals (SPAR, 1988; 2006)

These manuals, produced by Speech Pathologists in Adult Rehabilitation (SPAR) in 1988 and updated in 2006 provide a valuable source of drills, word lists and therapy ideas. Our original set, purchased by Dr Jill Lesic in 1988, also includes several additional manuals: Word Finding, Language Comprehension, Problem Solving and Memory.

2 Therapy manuals: Workbooks of activities for language and cognition (WALC), the Source series, and Handbook Of Exercises for Language Processing (HELP)

We find the following manuals to be the most useful in our practice: WALC 1 Aphasia Rehab (Tomlin, 2007); WALC 8 Word Finding (Tomlin, 2007); WALC 10 Memory (Tomlin, 2007); WALC 6 Functional Language (Bilik-Thompson, 2004); The Source for Oral-Facial Exercises (updated and expanded, Gangale, 2001); The Source for Dysarthria, second edition (Swigert, 2010); The Source for Alzheimer's and Dementia (Reese, 2000); The Source for Dysphagia, third edition (Swigert, 2007); The Source for Voice Disorders (Schwartz, 2004); and the Handbook of Exercises for Language Processing, vols 1 & 2 (Lazzari & Peters, 1987).

These practical therapy manuals provide a wealth of reproducible hard and soft copy work sheets and information.

3 Technology

Access to the internet and handheld devices provides us with many opportunities to source and/or develop therapy and education tools for a diverse range of clients. Examples of tools we find helpful for use in the aged care sector include:

printable AAC picture boards and therapy work sheets

- iPad applications specific to communication and swallowing. Apps we have found most useful include:
 - Swallowing Disorders by Blue Tree Publishing. This is a useful resource to demonstrate to clients, families and care workers what is potentially occurring due to dysphagia. The series of detailed images provides lay people with a visual representation of swallowing and dysphagia and can also assist in their understanding of the rationale behind recommendations for modified diets and/or fluids. It is available as a bundle of four apps for AUD\$18.99 from the iTunes App Store.
 - Speakit! 2: A text-to-speech app by Future Apps Inc., which is available for AUD\$2.49 on the iTunes App Store. It is compatible with iPhone, iPod touch, or iPad
 - Language TherAppy by Tactus Therapy, which is available for purchase through the iTunes App Store

 AUD\$59.99 (which includes four modules) from: https://itunes.apple.com/us/app/language-therappy/id525278822?mt=8
 - The Naming TherAppy module is also available on Google Play – AUD\$31.99 from: https://play.google. com/store/apps/details?id=com.tactustherapy. namingtherappy
 - Speech Sounds on Cue (Australian edition) by Multimedia Speech Pathology which is available for iPad only via the Apple App Store for AUD\$28.99 or via: http://www.mmsp.com.au/speech-sounds-oncue-for-ipad/
- Online courses:
 - Understanding Dementia MOOC University of Tasmania
 - The University of Tasmania offers a Massive Open Online Course (MOOC) that presents the latest international research in dementia studies. It is a free nine-week course that provides theoretical and practical information about dementia. At the end of the course, participants are presented with a certificate of achievement. Website: http://www.utas. edu.au/wicking/wca/mooc
 - Hand Hygiene (http://www.hha.org.au)
- Websites:
 - My Aged Care at www.myagedcare.gov.au Up-todate information about the aged care sector is readily available through this website
 - Fight Dementia at www.fightdementia.org.au has many informative help sheets available for downloading and printing.

4 A "word-finding kit"

This could include a collection of good-quality picture and photo cards and a collection of common objects (e.g., key, pen, comb, toothbrush, watch, spoon) all kept in a snap-lock bag. We commonly use such a kit for both assessment and therapy of language.

5 Good general knowledge

Good general knowledge about current affairs, sporting news, old movies, songs and actors from the bygone era; historical and cultural events which we can draw on to enhance conversations with our clients and which also form an important part of assessment and therapy.

6 A well-stocked "swallowing kit"



The contents of a standard swallowing kit could include:

- tub of puree (x1)
- tub of diced fruit (x1)
- thickener sachets
- plastic spoons
- plastic cups
- small plastic containers (for holding the fruit and puree once the tubs have been opened)
- · disposable gloves, small mirror and tongue depressor
- small pen torch for oral inspection
- slice of bread in a snap lock bag
- small savoury biscuits in a snap lock bag (e.g., Savoy buscuits)
- a banana in a snap lock bag (bananas are versatile as they can be used to assess swallowing of soft solids, mashed foods and smooth puree)
- a small cooler bag to store all the items
- samples of mucosa and denture treatments (e.g., Biotene and Polident).

7 Up-to-date information about diet and fluid categories, and associated handouts to provide to facilities and families

Companies such as "Flavour Creations" and "Nestlé" are a good source of information and educational material. We find that having a good relationship with the representatives of such companies is very useful should we have complicated questions about thickeners or require samples. We also have produced a series of handouts for clients, which are used regularly to inform families and facilities of appropriate options concerning specific diet categories.

8 The Dysphagia Cookbook

The Dysphagia Cookbook (Achilles, 2004) is an excellent resource to recommend to families and kitchen chefs who are interested in preparing creative modified meals.

9 Basic communication boards

We find it useful to have copies of laminated letter-based, number-based and "yes/no" type communication boards on hand. These have proven useful when clients, family members, carers or health professionals have expressed an interest in exploring AAC options. A small whiteboard and whiteboard markers have also proven useful.

10 Patience, kindness, compassion, and adaptability

Similar to working with other population groups in speech pathology, working with older persons can be at times challenging and varied. As a practice we have found that remaining patient, using kindness, and being ready to expect the unexpected have provided us with a foundation to form a strong rapport with our clients.

The patience to sit quietly with someone and hear their story or assist with their meal will reap rewards, both for the client and the therapist. This is especially poignant when working in end-of-life care. Being compassionate and realistic while still supporting the client and family is essential in this setting.

Maintaining a sense of humour and a genuine interest in another person's life journey enables us to make a positive and important impact in the lives of the elderly people we meet each day.

References

Achilles, E., (2004). *The dysphagia cookbook*. Nashville, TN: Cumberland House Publishing.

Bilik-Thompson, L. (2004). WALC 6 Functional language. East Moline, IL: LinguiSystems.

Gangale, D. C. (2001). *The source for oral-facial exercises updated and expanded*. East Moline, IL: LinguiSystems.

Lazzai, A. M. & Peters, P. M. (1987). *Handbook of exercises for language processing*. East Moline, IL: LingiSystems.

Reese, P. B. (2000). The source for Alzheimer's & dementia. East Moline, IL: LinguiSystems.

Schwartz, S. K. (2004). The source for voice disorders adolescent and adult. East Moline, IL: LinguiSystems.

Swigert, N. B. (2007). *The source for dysphagia*, 3rd ed. East Moline, IL: LinguiSystems.

Swigert, N. B. (2010). *The source for dysarthria*, 2nd ed. East Moline, IL: LinguiSystems.

Tomlin, K. J. (2007). WALC 1 Aphasia rehab. East Moline, IL: LinguiSystems.

Tomlin, K. J. (2007). WALC 8 Word finding. East Moline, IL: LinguiSystems.

Tomlin, K. J. (2007). WALC 10 Memory. East Moline, IL: LinguiSystems.

Correspondence to:

Dr Jill Lesic

Dr Jill Lesic & Associates Speech Pathology 3/976 Riversdale Road, Surrey Hills, Vic, 3127 phone: 1300 821 148; 03 9836 8542 email: jlesic@bigpond.com

website: www.jilllesicpathology.com.au

JCPSLP notes to authors

The *Journal of Clinical Practice in Speech-Language Pathology* is the major clinical publication of Speech Pathology Australia. Each issue of *JCPSLP* aims to contain a range of high quality material that appeals to a broad membership base. *JCPSLP* is published three times each year, in March, July, and November.

Issue	Copy deadline (peer review)	Copy deadline (non-peer review)	Theme*
Number 1, 2016	1 August 2015	1 August 2015	Prediction and Prognosis
Number 2, 2016	1 December 2015	1 December 2016	Shared decision making
Number 3, 2016	13 April 2016	13 April 2016	TBA

^{*} articles on other topics are also welcome

General

Material submitted must be your original work. Any direct quotations or material used from other sources must be credited in full. If copyright clearance is required to use material included in your article, please supply evidence that this has been obtained.

Ethical approval

All manuscripts in which information about a person and/or organisation is presented must be accompanied by evidence of approval by an authorised ethics committee. This includes clinical insights, ethical conversations, manuscripts presenting the results of quality assurance and improvement activities within workplace settings, and research manuscripts.

Themes

Each issue of *JCPSLP* contains a set of articles relating to a particular theme, as well as a selection of articles reflecting broader speech pathology practice. The Editorial Board selects a theme for each journal, and these themes can be suggested by members of Speech Pathology Australia at any time. Manuscripts on any topic relevant to speech pathology practice can be submitted to *JCPSLP* at any time.

Length

Manuscripts must not exceed 3500 words (including tables and a maximum of 30 references). Longer manuscripts may be accepted at the discretion of the editor. It is highly recommended that authors contact the editor prior to submitting longer manuscripts.

Types of Submissions

When submitting your article to *JCPSLP*, please indicate the type of submission:

- Tutorial: Educational/narrative discussion on topics of interest to clinicians.
 This should include a brief overview of the current literature, as well as a section containing clinical implications.
- Review: Critical appraisal of the research literature in an area of researchpractice that is relevant to practising speech pathologists.
- Clinical Insights: Articles that may be of primary clinical interest but may not have a traditional research format. Case studies, descriptions of clinical programs, and innovative clinical services and activities are among the possibilities.
- Research: Research articles with clear clinical relevance. These submissions
 will be judged on the review of the literature (including a rationale),
 methodology, statistical analyses, and a clear discussion directed to a clinical
 readership.

Peer review

Manuscripts submitted to *JCPSLP* undergo a double blind peer-review process. Regular columns (e.g., Webwords, Top 10, resource reviews) undergo editorial review. For peer-reviewed articles, *JCPSLP* uses a double-blind peer-review process, in which the anonymous manuscript is sent to two reviewers. The authors are provided with information from the review process. Often, authors are

invited to revise and/or resubmit their work, as indicated by the reviewers. Occasionally, the reviewers request to re-review the revised manuscript. In some instances, a paper will be rejected for publication. The editor's decision is final. The sentence "This article has been peer-reviewed" will appear after the title for all peer-reviewed articles published in *JCPSLP*.

Format and style

All submissions must be Word documents formatted in accordance with the following guidelines:

- All text should be 12 point Times New Roman, double spaced (except figures and tables), left justified.
- A maximum of five levels of heading (preferable 2-3 levels) should be used:
 - 1. Centered, boldface, uppercase and lowercase heading
 - 2. Left-aligned, boldface, uppercase and lowercase heading
 - Indented, boldface, sentence case heading with a period. Begin body text after the period.
 - Indented, boldface, italicised, sentence case heading with a period. Begin body text after the period.
- Indented, italicised, sentence case heading with a period. Begin body text after the period.
- Please use the terms 'speech-language pathology' and 'speech-language pathologist' (abbreviated to SLP) throughout article.
- Do not include images within the text of the article send photos as separate attachments, digital images should be of high quality and preferably be sent as uncompressed TIF or EPS images.
- Use only one space after punctuation, including full stops.
- Use a comma before 'and' in a series of three or more items (e.g., "The toys included a ball, bucket, and puzzle)
- Clear and concise writing is best. Use short sentences and paragraphs and plain English. Please reduce bias in language as much as possible (i.e., avoid stereotypical terms, refer to participants, rather than subjects, and be sensitive to racial and ethnic identity).
- Reproduce any quotations exactly as they appear in the original and provide the page number(s) for the pages you have quoted from.
- References, which should be key references only, must follow the American Psychological Association (APA, 6th Edition) (2008) style. Examples of correct in-text referencing and correct listing of references in the reference list are provided below. Please pay attention to the correct formatting, including the use of punctuation marks and case. For further details on correct referencing, visit http://owl.english.purdue.edu/owl/resource/560/01/. Note the referencing examples provided on the left hand side of the page.
- Tables and Figures: If there are to be tables or figures within your article, these should be presented on separate pages with a clear indication of where they are to appear in the article (in text indicate where the figure or table should be inserted). All tables and figures should be numbered. Figures should be presented as camera-ready art. Please ensure figures and tables appear at the end of your article with each table or figure on a separate page.

Documents to be submitted

- 1. Manuscript featuring:
 - a. Title
 - b. Author names and affiliations (will not be forwarded for peer review)
 - c. Up to 6 key words
 - d. Abstract (maximum 150 words)
 - Main body of text (main body must not include any identifying information)
 - f. Reference list (maximum 30)
 - g. Tables (if relevant)
 - h. Figures (if relevant)
 - i. Appendixes (if relevant)
 - j. Acknowledgements if relevant (will not be forwarded for peer review)
- 2. Author submission form (to be downloaded from JCPSLP website)
- A colour photograph of each author (to be included in manuscript if accepted for publication)

Submitting your manuscript

Articles should be submitted electronically to the Editor, David Trembath at icpslp@speechpathologyaustralia.org.au

