What is the speech pathologist's role in health literacy? Beyond our caseloads

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Health literacy is often thought to be the content provided as brochures, fact sheets, and other written information provided to clients. However, health literacy can be defined as being in three parts Moreira (2018). Currently, health information for the community is mostly developed by preventative health experts and population health experts working with communications and marketing professionals. Discipline-specific clinicians are often responsible for the specific health information used by their teams. It is an almost unknown consideration to plan for, let alone develop, other accessible means of communication for people's different communication and literacy needs. Yet literacy, and in particular health literacy, in the general community is poorer than is generally recognised. Currently, health literacy is not a priority area of work for speech pathologists. Yet many people in our communities experience barriers to effective communication.

Our health system is complex. It requires a range of different skills to be able to meaningfully access the parts of the system you need at the time you need it in the best way for you. Accessing new parts of the system, such as rehabilitation services, can bring about additional stress and anxiety.

In Australia, at least 1.2 million people, or 1 in 7 people, have a diagnosed communication disorder (Australian Bureau of Statistics [ABS], 2015). They, along with the rest of the community, engage also in the wider community, whether that is other health services or community, government, legal, and financial services.

The ABS (2013), partnering with Statistics Canada and the Organisation for Economic Cooperation and Development (OECD), has been collecting data on the literacy skills of adults aged 16 to 65 years since 1996. (ABS, 1996) In Australia, the data on literacy skills has not changed significantly since then; currently, 44% of the adult Australian population do not have the literacy skills to manage a range of day-to-day reading tasks, when it is measuring general reading prose. This data does not include rural and remote Aboriginal and Torres Strait Islander peoples, nor people who live in institutions such as prisons, nursing homes, community homes, forensic units, and boarding houses. The data also does not include new migrants or refugees. For people with English as second language, their literacy skills to read a range of day to day reading tasks, is 10% worse, being 54%.

By comparison, in the United Kingdom, the percentage of adults who do not have the literacy skills to manage a range of day to day reading tasks is 50%; in the United States, it is 52%. In some European countries, such as Italy, it is as high as 70% of adults in the age range 16 – 65 years. (OECD, 2013).

The data on numerical literacy indicates 53% of people do not have sufficient numerical literacy skills to manage regular day-to-day numerical literacy tasks. This is particularly relevant to health literacy, where concepts such as dosage, time, weight, amount, and comparisons require numerical literacy to complete tasks successfully. It also includes language like "repeat", "daily", and "as required".

A regularly quoted statistic is that almost 60% of Australian adults do not have the health literacy (i.e., the ability to read written information about health information) to engage in a range of day-to-day health reading tasks. This is based on extrapolating data from the ABS (2006) data to identify health literacy questions in their data set. It includes content such as an individual accurately reading and interpreting how to take their medication, attending an appointment correctly, and understanding treatment options and various costs.

This data is informing policies and strategies such as the *Australian National Preventive Health Strategy 2021–2030* (Commonwealth of Australia, (Department of Health), 2021) and the *Australian National Safety and Quality Health Service Standards* (Australian Commission on Safety and Quality in Health Care [ACSQHC], 2021). It is discussed in reports commissioned by the Australian Health Policy Collaboration such as *The state of self-care in Australia*, Duggan, Chislett, & Calder, (2017), and more recent reports such as *Self-care and health: by all, for all. Learning from COVID-19* (Duggan 2020) and *Self-care for health: a national policy blueprint. Policy paper 2020-01* (2020) Nichols, Calder, Morgan, Lawn, Beauchamp, Trezona, Byambasuren, Bowman, Clinton-McHarg, Willis, Kearns, Harris-Roxas, Duggan, Wardle, Litt, Menzies, Dawda, Benrimoj, Dineen-Griffin, (…), & Klepac-Pogrmilovic, (2020).

In 2018, the ABS Health Literacy Survey (ABS, 2018) was conducted, using a different set of measures to analyse aspects of health literacy over nine different domains, The Health Literacy Questionnaire. This involved participants' self-appraisal of statements across a 5-point scale from *strongly disagree* to *strongly agree* and *always easy to always difficult*. There were high positive ratings across all

domains, although like the ABS (2013) #4228, scores were lower for people with low incomes, people with multiple disease conditions, older adults, and people with English as a second language. This is useful information for overall service satisfaction and improvement measures but is not comparable with the earlier health literacy (reading and interpreting) data as these are self-reports rather than data obtained by measuring completion of an actual task.

Low levels of individual health literacy contribute to poorer health outcomes. Evidence shows that a person with low health literacy or low prose literacy has low general knowledge (ACSQHC], 2021) Hence, a person is less likely to know about preventative health measures compared with a person with good or high health literacy. They are more likely to visit their local doctor about a health condition at a more severe stage of their illness, have fewer choices about treatment options, and as a consequence have a higher mortality rate. Treatment options at the more severe stage are also likely to be more costly in economic, mental health, and other costs.

Many people with low literacy also have low digital literacy. As telehealth and access to health information on the internet is increasingly more widespread, it is also a barrier to accessing effective health information, knowledge, and choices. Accessing the internet requires literacy. Knowing that at least 44% of the adult Australian population do not have the literacy skills to manage a range of day-to-day reading tasks, accessing the internet is going to be very challenging for them. In addition, there are people who do have the literacy skills but not the digital literacy skills to manage a range of day-to-day digital reading tasks. This means that they can read information given to them in paper form but may not be able to locate information online by understanding how to search for and locate relevant information.

Furthermore, Campbell, Mason, Griffith, Dane, Reeson, O'Brien-McInally & Kimber, (2013) in their CSIRO investigation stated that one in five households do not have access to computers. Data from the OECD (2013) also found that just over one in five people opted out or were unable to complete the basic elements of using a computer. Only two in five people were able to use the internet at a level of competency to find and locate information. There is evidence, however, that some households with older people (aged 65+ years) changed some of their access and use of the internet during the COVID-19 pandemic. (Commonwealth of Australia (Australian Communications and Media Authority [ACMA], 2021). The report notes that uptake has mostly been in streaming and staying connected. Only a small number of people and amount of time were spent accessing health information.

In an earlier study from Thomas, Barraket, Wilson, Holcombe-James, Kennedy, Rennie, Ewing, MacDonald (2020), the Australian Digital Inclusion Index (ADII) for adults (aged 18+ years) reflects similar data. This index weights aspects such as access, affordability (in relation to income), and a person's digital ability to find what they need and to do what they want with technology. It reported that more than 2.5 million people were offline, and another 4 million people only used a mobile phone that limited data availability.

A report of the ADII in 2021 (Thomas, Barraket, Parkinson, Wilson, Holcombe-James, Kennedy, Mannell, Brydon, (2021) identified some changes during the pandemic. People with an already high or very high ADII had increased further. Those who previously had low ADII scores continued to score low. Therefore, the gap continues to widen.

Regulatory and policy drivers

The Australian Commission on National Safety and Quality Health Service Standards (2021) includes in Standard 2, Partnering with Consumers, the following expectations:

- Partnering with patients in their own care (P. 14)
- Health literacy. (p. 14)

Some specific elements include the following:

- Healthcare rights and informed consent …
  2.03 The … charter of rights … is easily accessible for patients, carers, families and consumers.… (p. 17)
- Sharing decisions and planning care
  2.06 …has processes for clinicians to partner with patients … to … communicate … their care. (p. 17)
- Communication that supports effective partnerships
  2.08 The … organisation uses communication mechanisms that are tailored to the diversity of the consumers who use its services (p. 18)
  2.10 … supports clinicians to communicate with patients, carers, families and consumers about health and health care so that:
  a) Information is provided in a way that meets the needs of patients, carers, families and consumers
  b) Information provided is easy to understand and use. (p. 18)

The *Speech Pathology 2030: Making Futures Happen* plan (Speech Pathology Australia, 2016) includes as three of their five aspirations

a) Communication accessible communities. (p. 7)
b) Access for all. (p. 9)
c) Skilled and confident families and carers. (p. 19)

In addition, the Speech Pathology Australia (2020) Professional Standards include a number of areas where accessible communication is included, being

- Domain 1. Professional conduct
  1.1. Provide ethical and evidence-based practice … obtain informed consent. (p. 11)
  1.5 Maintain high standards of communication … use accurate, accessible communication to respond to the needs of individuals and communities. (p. 12)
  1.7. Advocate for optimal communication and swallowing. (p. 12) This includes the United Nations (1948) *Universal Declaration of Human Rights* article 19 and the United Nations (2006) *Convention on the Rights of Persons with Disability* (UNCRPD) article 21. Both these articles refer to similar rights, being "Freedom of expression and opinion, and access to information". As described in the UNCRPD, article 21 states

  > States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in article 2 of the present Convention, including by:
  > a) Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost;

b) Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions;
c) Urging private entities that provide services to the general public, including through the Internet, to provide information and services in accessible and usable formats for persons with disabilities;
d) Encouraging the mass media, including providers of information through the Internet, to make their services accessible to persons with disabilities;
e) Recognizing and promoting the use of sign languages." (pp. 14 - 15)

What is health literacy?

Health literacy in the Australian context has been defined as being in two parts: the health literacy environment and the individual's health literacy capacity (ACSQHC, 2021). Moreira (2018), in *Health Literacy for People-Centred Care*, includes a third part—that is, the health system in which a person operates. How these three areas work together represents the overall health literacy of an individual in their community.

The health system

It is recognised that the health system is complex. Person-centred health care requires the health system to plan the changes required at a structural, policy, and practice level to implement improved health literacy across its organisations and for the people who interact with it.

The environment

Information is provided to clients and patients by experts in their fields, such as speech pathologists, physiotherapists, or medical practitioners. We become familiar with the language of our disciplines, often overlooking how specialised some of our language is.

Discipline-specific language

Discipline-specific language and knowledge is not the language or life experiences and knowledge of our clients. Clinicians should explain what is happening, treatment options, and other things that are needed in a way the client understands. Does this happen in every interaction with every health professional?

As communication specialists, speech pathologists should be able to modify their language and explain information to the client and family—whether it is a test result, a plan for implementation, or how long you will work together—in a way they understand and can use in a meaningful way.

An ongoing clinical skill of speech pathologists should be to reflect on whether the language and support tools they use every time they communicate with their clients, their families, and their networks are the most effective for them at that time. Is there a role for speech pathologists in sharing their communications expertise with the rest of the treatment team, whether they are medical, allied health, teachers, or the administrative members of the team?

Some specific considerations for good health literacy environments are discussed in the 2014 ACSQHC guide *Health literacy: Taking action to improve safety and quality*. They include

- the relationships team members have with their clients and their families,
- the assumptions made about their communication skills, This must also include assumptions about the best language to communicate in and cultural awareness for different families and cultures,
- consideration of the language and assumed health knowledge of the client and their family and clinicians modifying their communication to meet the clients' needs, checking with the client and family about their understanding of what has been talked about.

Speech pathologists would specifically add do not make assumptions about the communication skills of the person or their communication partner, including any verbal as well as alternative or augmentative needs for communication.

Individual health literacy

This attribute relates to how an individual can read, understand, and use written health information. Once read, they are expected to evaluate and make meaningful decisions about their health. This relies on them being able to construct meaning from the text based on their own lived experience and their health general knowledge. Then, they need to know what to do with the information.

As essential as a person correctly taking their medication and understanding the treatment steps for their care is the knowledge, understanding, and actions in the preventative health sphere, such as health screens for cancer, understanding about vaccines, or healthy eating plans.

Speech pathologists and other health professionals can learn to write what is described as health literacy information. It involves removing complex or technical health information and writing it in a plain language style. Generally, this should have a reading equivalence of an average Australian high school Year 9 student, which is approximately the level of a 15-year-old reader. This plain language health literacy information, though, is only readable for the 40% of the population who have good or high health literacy.

Access to health information must consider a range of different audiences, including those with low health literacy. These may be, but is not limited to,

- people with lifelong disabilities,
- people with acquired disabilities, who may or may not have had different literacy prior to their disability,
- people who read English as a second (or third language),
- people who are Deaf and use Auslan,
- people who are vision impaired who use braille or require large print.

People with low literacy also may include those who have an oral first language, poor school attainment, an interrupted education such as refugees, homeless people, people with mental health illness, or people who are ageing; and many others.

When engaging with the health sector, it is likely that a person is unwell, time poor, or anxious about the situation. With these added factors, being able to read a complex or unnecessarily wordy form, fact sheet, or brochure is potentially a barrier for us all. everyone.

Hence, health information written in Easy English is one of a number of versions of content that needs to be accessible and available to the public. It needs to be part of business-as-usual practice rather than for a specific person who may be identified as having low literacy.

Easy English

Easy English has been developed in Australia over the last 18 years. Its intended audience is any person with low literacy. The content and images are selected to meet the diverse needs of the audience of that particular content. Although there is significant debate about the use of readability scales, it is one point of comparison to consider in developing Easy English.

Current evidence (Basterfield, 2021a, 2021b, 2021c, 2022a, 2022b) indicates Easy English has a reading grade equivalence of Grade 0 to Grade 3, with an average of Grade 2, according to the Flesch-Kincaid reading scales (Flesch (1948). There are a maximum of four images per page. It is tailored to the intended audience, which may or may not be a person with intellectual disability.

Easy English uses simpler text, including word length, sentence length, number of syllables per word, and use of morphemes compared with Easy Read (Basterfield, 2017a, 2017b, 2017c; 2018a, 2018b; 2021a, 2021b, 2021c; 2022a, 2022b). Easy Read was originally developed in the United Kingdom and has a reading equivalence of U.S. Grade 4 to Grade 14, with an average of Grade 5 (Buell, 2019). Analysis of Easy Read developed in Australia shows it also has an average of Grade 5 reading equivalence. (Basterfield, 2018a, 2018b; 2019a, 2019b, 2019c; 2021a, 2021b, 2021c; 2022a, 2022b).

As explained earlier, health literacy is a three-part process. It is (a) the systems, polices and practice of an organisation, (b) how the people in the environment consider the needs of individual clients in communicating with them, and (c) the provision of accessible written health information and appropriate staff support so the client can read, understand, and know what to do with that information. It does not matter whether it is for Easy English, large print, a screen reader, in plain language, or in other accessible forms.

As speech pathologists, we have expertise in building awareness and teaching others about communication interactions and what communication partners can do. We can provide additional supports for people who have difficulty understanding, along with augmentative and alterative communication.

In addition, as language and literacy experts, speech pathologists have the skills and knowledge to know how to simplify content and consider aspects such as vocabulary choice, length of sentence, sentence structure, and grammar for oral or written communication.

Implementing whole-of-organisation health literacy would have positive implications for individual clients as the health system and health environment are now better supporting their needs. This should take place not just because a client is there but as a strategic, planned part of everyday interactions with everyone.

An example of how speech pathologists can and must take a leading role in changing health literacy has been during the current COVID-19 pandemic. This is discussed next.

Health literacy including Easy English during the COVID-19 pandemic

The system

The Australian Government Department of Health and Aged Care provided information on what safeguards to put in place for our own health and community safeguards that everyone was asked to follow. During the early phases of 2020, this information was provided daily via press conferences and press releases, and eventually, some plain language fact sheets were available on their website (www.health.gov.au).

Initially, the federal and state governments had no content in any accessible formats. Later, it was learned that there had been no plans to develop content in accessible formats. Action by advocates and their allies prompted the development of some information in accessible formats. Eventually, a small proportion of accessible content was coordinated by the federal and state governments.

Being aware of the Australian literacy skills data, the Australian National Safety and Quality Health Service Standards' regulatory framework (2021), and the UNCRPD (2006) obligations, this was clearly not enough.

Individual health literacy: Easy English

Access Easy English developed more than 120 Easy English COVID-19 public health information fact sheets and posters during the 6 months from March to August 2020. These were based on official government publications and announcements. They included 35 fact sheets and posters based on content from the federal government, four posters and three fact sheets based on World Health Organization information, and 82 fact sheets and posters covering state government content, ranging from rule changes and hotspots to border closures and major sport. Content was usually available within 24 hours of being announced. This work was completed pro bono.

To put these numbers into context, this compares to just 25 documents published by federal and state governments combined for people with lower literacy. Often, this content was taking up to 5 weeks to be published following announcements.

The outcomes of the Easy English content development were requests from disability organisations and others for specific topics, such as *What is PPE? How to Wear a Mask*, and *Why Do We Need These Rules*.

Environment

We are unaware of any print versions of any plain language or other documents being distributed by the federal government. The government relied on people accessing the Department of Health and Aged Care website for specific details, as well as television, radio, and social media posts.

Distribution of the Easy English publications relied on the goodwill of local, state, national, and international connections via the Access Easy English website and social media. It also relied on people printing off the content for the people they were supporting. One person accessing a link to the website could have been sharing copies with just one other person or many more people. It may have been printed and put on a notice board or further sent by email to other people. It is unknown what the true figure is of its usage.

The significantly increased traffic to the Access Easy English website shows we were meeting an ongoing need. Reports from other organisations that listed links on their websites also reported at least similar traffic numbers. Some of these also provided evidence of how valuable this content was to the wider community, such as the Australian Federation of Disability Organisations, Community Connective, Ethnic Council of Victoria Health

Translations, Speech Pathology Australia, Humans Like Us (migrant and refugee communities), Ideas (a disability information and resource hub), Tasmanian Council of Social Service (TasCOSS), and Universal Design Australia.

It is unknown how people with low literacy were supported to use the information in Easy English. However, disability advocacy groups reported that people asked for Easy English content, suggesting there were positive interactions and actions that could be taken by the readers.

Conclusion

Health literacy is a multifaceted approach to improving the health journey of the people we engage with clinically, as well as of the many other people on their health journeys. Speech pathologists have a breadth of skills that enable them to be better engaged in this process. Having an international, national, and professional regulatory framework enables this to occur.

Our work can influence the specific area of individual health literacy and increasing awareness of the need for other accessible means, such as Auslan. Together with support and training for other professionals to improve communication interactions, and working at a policy level, all people who enter the health system should have access to improved health literacy.

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