Patient and carer information: Can they read and understand it? An example from palliative care

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Literacy is considered to be the ability to read and write, with health literacy defined as having the knowledge and skills required to understand and use health information to make informed decisions (Cloonan et al. 2013).

Health literacy is vital to effective communication between health professionals and patients, and is associated with adverse patient outcomes (Berkman et al. 2011). With increasing numbers of the population accessing technology, the concept of ehealth literacy has also emerged in the literature, encompassing the ability to use computers, search for and understand online information and be able to put it into context (Norman and Skinner, 2006). This paper looks at the important issue of health literacy, providing an example from an Australian palliative care website.

Literacy is a complex concept, incorporating such aspects as information literacy, technology, or visual literacy but simply described as: "to confidently and appropriately read, write, speak and listen in a range of contexts" (Queensland government, 2014).

For nurses, there are common indicators of low literacy to be aware of, which Ennis and colleagues (2012) describe as 'red flags', including:

- making excuses when filling out forms ("I don't have my glasses");
- pointing to, or following the text when reading;
- missing appointments;
- issues with medication adherence or compliance;
- avoiding situations where complex learning is needed, or providing incorrect feedback when questioned about what they have read (Cornett, 2009).

It is important to recognise that low literacy does not equate to low intelligence, as many of those who are illiterate are very intelligent and often skilled at hiding their poor reading skills from others.

Health literacy

A definition of health literacy from the National Library of Medicine (2013) is: "the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions". Lower health literacy is associated with adverse patient outcomes, including higher hospital re-admissions, lower utilisation of preventative services, taking medications inappropriately, greater use of emergency services and higher mortality rates in older people (Berkman et al. 2011).

In the 2006 *Australian Adult Literacy and Life Skills Survey*, 41%

59%

HAD DIFFICULTY WITH TASKS SUCH AS LOCATING INFORMATION ABOUT THE MAXIMUM NUMBER OF DAYS A MEDICINE COULD BE TAKEN

of adults were assessed as having adequate or better health literacy skills (Level 3 or above), regarded as the minimum required to allow individuals to meet the complex demands of everyday life (Australian Bureau of Statistics, 2009). Results also showed that 19% of adults had Level 1 health literacy skills, and 40% had Level 2, indicating that 59% had difficulty with tasks such as locating information about the maximum number of days a medicine could be taken (Australian Bureau of Statistics, 2009).

Health professionals don't always recognise the limitations of their readers when creating patient information, or in clinical encounters when using jargon instead of plain language explanations (Coleman, 2011), underestimating its relevance to the general population (Mackert et al. 2011). A person's health literacy is indicative of their ability to be an equal partner in making health decisions, so if nurses are unaware of low health literacy levels in the population, they cannot address it in practice.

Considerations must also be made for those from culturally and linguistically diverse (CALD) backgrounds, and for Aboriginal and Torres Strait Islander (ATSI) people who don't have English as a first language. Literacy and/or health literacy in these individuals may be further complicated by their having to translate information that they may or may not understand into or from their own language (Ishikawa and Yano, 2008). Interestingly, nurses will often compensate for CALD patients in both information provision and in explanations, but may not always take into account that other patients may have low health literacy as well. However, saying that, in their study of midwives providing antenatal care, Wilmore and colleagues (2014) found that nurses used various strategies "to try to ensure that people understood the health messages and information that they delivered" (Wilmore et al. 2014). In effect, the nurses found it necessary to change the way in which they utilised the written materials for some patients, indicating that they felt them to be too complicated to be understood (Williamson and Martin, 2010).

Reading level is an important component of health literacy, and

readability formulas remind us that patient information should match the reading skills of the intended user. The readability of a document refers to the comprehension level a person must have to understand the information (Schmitt and Prestigiacomo, 2013).

The Flesch reading score is a valid and reliable formula for the measurement of readability (comprehension difficulty) in a document (Flesch, 1948). The Flesch-Kincaid Grade Level rates text on a US school grade level, meaning that a 6.0 rating indicates that a sixth grader should be able to understand the documents (Kunz and Osborne, 2010). This is the same as Grade 6 in Australia where students are approximately 11-12 years old. This is likely a lower level than the reading ability of the average American or Australian but a lower readability score in health information terms, helps patients to understand unfamiliar medical terms and concepts (Williamson and Martin, 2010).

> **HEALTH PROFESSIONALS DON'T ALWAYS RECOGNISE THE LIMITATIONS OF THEIR READERS WHEN CREATING PATIENT INFORMATION, OR IN CLINICAL ENCOUNTERS WHEN USING JARGON INSTEAD OF PLAIN LANGUAGE EXPLANATIONS**

By employing these formulae (found in Microsoft Word) an author can for example, modify the length of sentences and substitute shorter words which in turn help to make a piece simpler to read. However, it should be noted that these formulae are not perfect (Stossel et al. 2012), and for example, in reducing sentence length too much, the subsequent information can be interpreted as patronising to the reader (DR personal conversation with a palliative care social worker, 2013). While not the complete solution, readability is an important precursor to health literacy and

readability scores can provide a first indicator of the need to revisit a document or webpage. It must also be acknowledged that applying readability scores will not account for poor grammar, typographical errors, and vague language (Taylor and Bramley, 2012).

Various authors have retrospectively screened patient information with a view to assessing readability, such as Terblanche and Burgess (2010) who looked at consent forms that had been used in research for nine years finding that all 84 forms were too complex to be understood by the average study participant, which could easily lead to problems such as therapeutic misconceptions. Similarly, Taylor-Clarke and colleagues (2012) looked to the readability scores of 18 patient education materials from local heart failure clinics and from the internet, finding only two that had ideal suitability and readability. Williamson and Martin (2010) also screened 171 patient information leaflets available in a hospital, with the majority exceeding patient comprehension.

One Australian study looked at health literacy from the patients' perspective, identifying several areas of concern: knowing when and where to seek health information, explaining the health problem to health professionals and understanding their responses to it, clarifying information received, following up on information after the conversation, the capacity to process and retain information (emotional and physical) and the ability to follow instructions (Jordan et al. 2010).

There were also a range of factors at the healthcare level (such as a health professionals' approach or their trust in them) and broader community level (culture, education and socio-economic) that affect these abilities. A suite of strategies to increase understanding and readability is required.

Cloonan and colleagues (2013) describe successful strategies to address low health literacy that include: teach back methods, jargon-free communication, tailored messages and early assessment of post-discharge needs.

Teach back methodologies are one well evaluated way in which nurses can confirm that a patient has understood what they have been told. For example, many

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patients will automatically say "yes" when asked if they have understood something. Others may immediately forget what they have been told or even misinterpret it in the first place. Asking them to repeat back in their own words the instructions they have received can confirm their understanding.

It is not only important to develop interventions aimed at nurses but to recognise that healthcare organisations also share a responsibility to become more health literate (Parker and Hernandez, 2012).

The Australian Commission on Safety and Quality in Health Care (2013) recommend strategies to address health literacy in a coordinated way in Australia, which can be facilitated by including signage around buildings, easy to complete registration forms, engaging consumers, and educating all staff (including front-line and administration).

Ehealth literacy

With more and more of the population accessing technology, the concept of ehealth literacy has also emerged, which encompasses the ability to use computers, search for and understand online information and be able to use it effectively in decision making. A survey conducted in America in 2012, found that 81% of adults used the internet and, of those, 72% said that they had looked online for health information in the past year, so legitimate concerns about readability of patient information also apply to online arenas (Fox and Duggan, 2013). In terms of sourcing and understanding health information on the internet, there is likely a link between ehealth literacy and technology use (Norman and Skinner, 2009).

Many consumers are using the internet for health information, but cannot always do this well, coming away with false or misleading information which in turn can have adverse health outcomes. The ehealth literacy scale (eHeals) is a self-report tool designed to assess consumers' ehealth skills which can support clinical care (Norman and Skinner, 2009).

Walsh and Volsko (2008) randomly sourced consumer targeted web pages from five American chronic disease websites (eg. American Heart Association), finding that more than three quarters of the articles had a reading level requiring higher education to understand them. A PhD study of online palliative care documents included in HealthInsite, an Australian consumer resource, found that around 60% of documents would require some university level education to read. Reading levels for 40% of the retrieved items were seen to be as complex as reading tax legislation (Tieman, 2011).

An example from practice

Palliative care will affect most people whether as a patient, carer, family member, neighbour or friend. Each of these people may need different information, given in different ways at different times in the disease trajectory.

This may depend on: who they are; their outlook on life and on serious illness, and their culture or upbringing.

While it is important to provide good quality information, it is also important that the information provided can be easily read and understood (Walsh and Volsko, 2008).

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CareSearch (**www.caresearch.com.au**) is an Australian website that provides information and resources for anyone providing palliative care and anyone affected by the need for palliative care. The website is funded by the Department of Health and has been in existence since 2008. The quality processes built into the website ensure that the information is evidence based and that it is easy to read and to understand. The following case study provides information on some of the processes used to ensure a quality product.

> MANY CONSUMERS ARE USING THE INTERNET FOR HEALTH INFORMATION, BUT CANNOT ALWAYS DO THIS WELL, COMING AWAY WITH FALSE OR MISLEADING INFORMATION WHICH IN TURN CAN HAVE ADVERSE HEALTH OUTCOMES

Case study

CareSearch has a suite of pages written especially for patients, carers and families, with quality processes in place to guide the development of the content. This included training page authors in writing for the web and employing readability scores when writing. An advisory group supported the page author, in this case drawn from those who represent or work alongside patients and their families: Carers Australia, Consumer Health Forum, Palliative Care Nurses Australia and the Federation of Ethnic Communities Councils of Australia. The group provided feedback which led to the inclusion of more visual images and videos, increased font sizes (accessibility - tested for the visually impaired), changes to page layouts, changes to the content architecture, and new content. The use of dot points, well-spaced information, sub-headings, colour on pages and text size options also help to make pages easier for the intended audience to read.

Usability testing was employed, with a group of intended users (in this instance consumers) testing how easy the pages were to navigate, to read and to understand. The readability scores of each page was aimed at a Flesch grade of 6-7.

The CareSearch project team considered web design, even when readability scores are at a suitable level, the way in which information is displayed on a website can affect how easy it is to read.

Staff ensured compliance with the standardisation of web technologies (W3C and WCAG 2.0 standards) which ensures that the content is accessible for people with disabilities.

These quality processes have helped to improve the presentation and usability of the *For Patients, Carers, Families* pages. **www.caresearch.com.au/caresearch/tabid/64/Default.aspx**

Recommendations for practice

Nurses are often in a position where they are required to provide written information for patients. This may be instructions regarding medication compliance or a certain task to be performed at home. Acknowledging that there are large numbers of patients who do not read well, or who struggle to understand health information, is vital. There are skills and strategies that nurses can use to make sure that what they are providing, or communicating to, patients will increase the likelihood that it can be more easily read and understood.

Some of these are:
- use a larger text/font size;
- include images, diagrams or videos (Walsh and Vosko, 2008);
- present numerical information in tables (Sheridan et al. 2011);
- slow down when talking (Williams, 2002);
- provide information about medications (Cloonan et al. 2013);
- revise sentence structure, use plain language and remove jargon (Hunter et al. 2012);
- usability testing (ask non-health professionals to read a leaflet, brochure or web page and get them to tell you what it means can also confirm how well the message has been delivered);
- limit the information provided at each interaction, and focus on the most important (Peters et al. 2007).

When creating content for websites there are also specific considerations (see Table 1) which health professionals are also not always aware of.

> **Table 1 Checklist for consideration in the web environment**
> 1. Are staff familiar with writing for the web?
> 2. What readability levels have been set and how are they decided?
> 3. Are intended users involved in content development and processes?
> 4. Are templates used to help ensure consistency?
> 5. Are images appropriate to reinforce the message?
> 6. Could the message be delivered in another format eg. video
> 7. Are font sizes and styles appropriate?
> 8. Are pages W3C compliant? (ie. accessible)
> 9. Would user testing be useful?
> 10. Would page editing help?

Conclusion

Health literacy and ehealth literacy are emerging concepts in the literature, highlighting that large numbers of patients and carers cannot read or understand either written or online information to help them to make decisions about their health.

Nurses provide information for patients, often in the form of a written brochure or leaflet, not always considering that many are unable to read it. Using defined quality processes increases the likelihood of producing materials that can be understood by patients and carers.

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