
Bridging the communication divide for patients with blood cancers

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Service Improvement

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Summary

When a patient is being tested for or has received a blood cancer diagnosis it is not only overwhelming and life changing, but the treatments can be lengthy and complex and often require

patients to be urgently admitted to hospital and they often don't get to return home for months. To assist with this, face to face education sessions are given to patients and families and patient consent gained, prior to any treatment commencing. These sessions are usually accompanied by giving patients handouts and booklets for further review and consolidation of information. Through treatments, patient empowerment and engagement in self-care practices is essential and encouraged to assist the treating team manage and reduce the side effects of treatment. We noted a significant deficit in the suitability of current patient booklets and resources for people with low English literacy or resources which acknowledged and addressed Aboriginal and Torres Straits Islander patients. Resources were heavily text based, with few graphics and did not assist the clinician to easily bridge the communication divide for the various patient cohorts with low English literacy. There was a distinct need for information booklets which were pictorial-story based, to transcend language and literacy barriers. Applying clinical knowledge and interest in art and in lengthy consultation regarding cultural safety and clinical content with Haematology teams, Indigenous health workers and patients, I developed five evidence - based, pictorial booklets, primarily pitched for Australian Indigenous patients diagnosed with a hematological malignancy. The booklets use the visual medium of illustrations and simple wording, commonly used by Indigenous Australians such as 'mob' for people to transfer information. It is vital for patients to feel informed and understand what is being explained to them when consenting to treatment. Patients also need to understand and feel empowered to engage in self-care. Having simple, clear information displayed predominantly through graphics with a reduce volume of text, and using text that is conversational with little medical jargon, can assist the clinician to impart information by appealing to their visual as well as audible learnings styles (Very well mind,2024).

The booklets cover the likely one to two years of intensive treatments, including the complexities of auto and allogeneic stem cell transplants. The graphics are specific and colourful and even explain basic anatomy such as, what cells are, as many Indigenous languages do not have a word for 'cell', which makes discussions of 'sick'• cancer cells challenging. The booklets met favorable reviews from all parties engaged in their evaluation and agreement was reached that there were deficits in the resources available for First Nations Australians and those with low English literacy. In September 2023, the Leukaemia Foundation of Australia, endorsed the booklets and became the repository for patients and clinicians to freely order or download these resources to support their comprehension needs.

Key dates

Jul 2017

Jun 2023

Implementation sites

Longreach Hospital

Partnerships

Patients and carers; Indigenous and Torres Strait Islander health Workers and Liaison Officers; Haematology Doctors and Nurses; Leukemia Foundation

Key Contacts

Simone Thomason

4504

william.vanheerden.ced

Nurse Navigator, Longreach Hospital

Central West Hospital and Health Service

Tel: 07 46525526

simone.thomason@health.qld.gov.au

Aim

- Applying clinical and cultural knowledge to develop evidence-based pictorial booklets, primarily pitched for Australian Indigenous patients diagnosed with a hematological malignancy.
- The booklets aim to ensure indigenous people are acknowledged and are front and center in the message, whilst still providing content for all viewers to draw information from.

Benefits

The positive feedback and uptake of the booklets has led to discussions with the Leukaemia

Foundation and myself, to develop the resources digitally into videos, with voice overs in Indigenous Australian languages, English and other languages to further support the needs of patients and families. Digitally, these can be played in wait rooms, on individuals' phones and devices and reach a wider audience.

Furthermore, the success of the booklets has led to discussions with the Cancer Council of Queensland, to undertake illustrated booklets, pitched for Indigenous Australian men and women diagnosed with a solid or oncological cancer or people with low English literacy or culturally and linguistically diverse backgrounds.

Background

In 2014-15, just over one-third (37.9%) of people aged 15 years and over whose main language spoken at home was an Aboriginal or Torres Strait Islander language reported experiencing difficulty understanding and/or being understood by English speakers (ABS,2021). Having health literacy is 'the ability of individuals to gain access to, understand and use information in ways which promote and maintain good health' (ABS, 2018). When it was evident that a significant volume of people in my care, had low levels of English and knowing the impact this can have on their ability to access services and achieve optimal health outcomes, I set out to develop pictorial evidence-based resources to meet their comprehension needs. After reviewing current resources, it was evident that many resources did not always depict Indigenous people, and this can further alienate the Indigenous reader from identifying with the message.

Solutions Implemented

Applying clinical knowledge and interest in art and in lengthy consultation regarding cultural safety and clinical content with Haematology teams, five evidence - based, pictorial booklets were developed, primarily pitched for Australian Indigenous patients diagnosed with a hematological malignancy. The booklets underwent extensive reviews, for cultural safety and sensitivity by Indigenous health workers and liaison officers, patients and families. And clinical content was reviewed by a team of hematologists, nurses, pharmacists and members of the Leukaemia

Evaluation and Results

The booklets met favorable reviews from all parties engaged in their evaluation and agreement was reached that there were deficits in the resources available for First Nations Australians and those with low English literacy.

References

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