Shared Decision Making and Health Literacy

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What is health literacy?

- >17 definitions of health literacy; >12 conceptual models\(^1\)

- WHO definition: “the ability of individuals to gain access to, understand and use information in ways which promote and maintain good health”.\(^2\)
Why do we care about health literacy?

- The only nationally representative survey to directly measure health literacy skills in Australia found that:
  - 60% of Australian adults lack functional health literacy skills (e.g. interpreting medicine labels)\(^3\)

- Impact on health: hospitalisations, emergency use, screening and preventative behaviours, overall health status and mortality\(^4\)

- Social gradient: lower levels of health literacy more common among the socially and economically disadvantaged (e.g. older adults, CALD groups)\(^3\)
The two sides of health literacy

Risk v asset models of health literacy

Risk approach\textsuperscript{5}

• Health literacy as an individual deficit / static patient characteristic.

• Poor health literacy is viewed as a risk that leads to poorer health outcomes and reduced compliance with health care advice.

• Efforts to improve health literacy tend to be goal-directed, seeking to mitigate the related risks to achieve improved clinical outcomes. E.g.
  • Simplification of health information and advice
  • Modifications to service organisation.
## Risk v asset models of health literacy

<table>
<thead>
<tr>
<th><strong>Risk approach</strong></th>
<th><strong>Asset approach</strong></th>
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<td>• Health literacy as an individual deficit / static patient characteristic.</td>
<td>• Health literacy as a personal asset / modifiable health determinant which offers consumers greater autonomy and control over healthcare decisions.</td>
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<td>• Poor health literacy is viewed as a risk that leads to poorer health outcomes and reduced compliance with health care advice.</td>
<td>• Health literacy is subject to change and improvement.</td>
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<td>• Efforts to improve health literacy tend to be goal-directed, seeking to mitigate the related risks to achieve improved clinical outcomes. E.g.</td>
<td>• Interventions seek to build skills and capacity.</td>
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Involving patients in decisions about their health: Focusing on demands and complexity
Reducing demands and complexity

Decision aids
how they can benefit you

what are decision aids?

paper or electronic tools that contain information about a specific health condition and available treatment options

how can they help me?

they can help you:

• identify your treatment options
• make informed decisions
• compare the risks and benefits
• make treatment decisions based on what matters to you

Image created by Australian Commission on Safety and Quality in Healthcare
Demands and complexity – Early findings

- Readability and cultural sensitivity of web-based patient decision aids for cancer screening and treatment: a systematic review – 2007

- Evaluated 23 decision aids
  - 74% (n = 17) written at the grade 10 – 13
  - 22% (n = 5) at the grade 9
  - 4% (n = 1) at the grade 8 level

Recommended Grade level for adults with lower literacy = Grade 5
Demands and complexity – Early findings

- Addressing health literacy in patient decision aids - 2013

- 97 trials of patient decision aids
  - Only 3 addressed the needs of lower literacy or education audiences

- In 90% of the trials, neither the readability of the decision-aid or the health literacy of the audience were reported
Demands and complexity – Solutions

Assessing the usefulness and acceptability of a low health literacy online decision aid about reproductive choices for younger women with breast cancer: the aLLIAnCE pilot study protocol

Michelle Peate, Sian Karen Smith, Victoria Pye, Alice Hucker, Cathryn Stern, Lesley Stafford, Catherine Oakman, Laura Chin-Lenn, Kerry Shanahan, Nipuri Ratnayake Garnage and Martha Harris

Use of Low-Literacy Decision Aid to Enhance Knowledge and Reduce Decisional Conflict Among a Diverse Population of Adults With Rheumatoid Arthritis: Results of a Pilot Study

Jennifer L. Barton, Laura Trupin, Dean Schillinger, Gina Evans-Young, John Imboden, Victor M. Montori, and Edward Yelin

Effectiveness of a Web-Based Colorectal Cancer Screening Patient Decision Aid
A Randomized Controlled Trial in a Mixed-Literacy Population

David P. Miller Jr, MD, MS, John G. Spangler, MD, MPH, L. Doug Case, PhD, David C. Goff Jr, MD, PhD, Sonal Singh, MD, MPH, Michael P. Pignone, MD, MPH
Demands and complexity - Solutions

- Readability scores
- Patient Education Materials Assessment Tool (PEMAT)
- Suitability Assessment of Materials (SAM)
- Universal Precautions Toolkit
Demands and complexity – Solutions

- Toolkit to Make Written Materials Clear and Effective

- Health Literacy Online: A Guide for Simplifying the User Experience

- Simply Put: A guide for creating easy-to-understand materials

- Everyday Words for Public Health Communication
Resources

This section of the website provides access to resources that our community of practice have used and recommend to others. It provides practical tools, publications, policies and guidelines to support the improvement of health literacy including advice on:

- written and verbal communication
- accommodating the needs of diverse populations
- communicating risk.

The links are checked regularly and updated from time to time as new information becomes available.
Demands and complexity – Outcomes

- Developed a decision aid for adults with low education and literacy to support informed choice and involvement in decisions about screening for bowel cancer\(^8\).

  • Reduced text
  • Glossary of medical terms
  • Active voice
  • Lay language
  • Illustrations
  • Simplified medical diagrams
Demands and complexity – Outcomes

- Evaluated in a randomised controlled of 572 adults aged between 55 and 64.8

- Compared decision-aid to standard information about the Australian bowel cancer screening program.

- Decision aid increased knowledge and informed choice mong adults with low levels of literacy and education (without increasing anxiety or worry) compared to control.
Reducing demands and complexity – Verbal communication

Early stage breast cancer: What’s right for me?

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<tr>
<th>Frequently asked questions</th>
<th>Lumpectomy with radiation</th>
<th>Mastectomy</th>
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<tr>
<td>Will it affect how I feel?</td>
<td>Breast cancer will come back in the breast in about 10 in 100 women (10%) in the 10 years after a lumpectomy. Recent improvements in the treatment may have reduced the risk.</td>
<td>Breast cancer will come back around the scar in about 5 in 100 women (5%) in the 10 years after a lumpectomy. Recent improvement in the treatment may have reduced the risk.</td>
</tr>
<tr>
<td>Will cancer come back in the breast?</td>
<td>Only the cancer lump is removed.</td>
<td>The whole breast is removed.</td>
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<td>What is removed in the breast?</td>
<td>Possibly, 20 in 100 women (20%) might need another operation.</td>
<td>No, unless you choose breast reconstruction.</td>
</tr>
<tr>
<td>Will I need more than one operation?</td>
<td>Most women are home within 1 day after surgery. It will take about a week before you can resume usual activity.</td>
<td>Most women are home within 1 day after surgery. It will take several weeks, sometimes longer, before you fully recover and can resume usual activities.</td>
</tr>
<tr>
<td>How long will it take to recover?</td>
<td>Yes, it will mean repeated visits to the hospital, possibly several times a week, for up to 6 weeks after surgery.</td>
<td>Radiation is not usually given after a mastectomy. You will be able to resume usual activity.</td>
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<td>Will I need radiation?</td>
<td>Yes, for both options, some or all of the lymph nodes in the armpit are usually removed.</td>
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<td>Will my lymph nodes be removed?</td>
<td>You may be offered chemotherapy, but this does not depend on the operation you choose. Hair loss is common after chemotherapy.</td>
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<td>Will I need chemotherapy and lose my hair?</td>
<td>Both options have similar costs. You need to know upfront what is covered by your insurance and what are the out of pocket expenses. Do not hesitate to ask questions to your doctor and care team. They will know who can help and give you answers. If you cannot pay, are uninsured and do not qualify for Medicaid, there are various programs available to help you, speak to a doctor or to someone else in the care team.</td>
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Image 1: Alam et al. BMC Medical Informatics and Decision Making (2016) 16:147
Image 2: https://shareddecisions.mayoclinic.org/
Reducing demands and complexity – verbal communication

- Teachback
  - Iteratively asking the patient to summarise or restate the important points in a consultation using their own words

What is teach-back?

Teach-back is a simple yet effective communication tool used to check understanding.

Teachback.org
Involving patients in decisions about their health: Focusing skills and abilities
Preparing patients to be involved

- Many patients currently feel that they can't participate in shared decision making.\(^9\)
  - Irrespective of literacy / education
Preparing patients to be involved

- Inform patients about shared decision making
- Explain that there are two experts in the clinical encounter – patient and clinician
- Challenge attitudes that there are right and wrong decisions
- Redefine perceptions of a good patient and reassure patients that participation will not result in retribution
- Promote social acceptability of this role
- Build patients' belief in their ability to take part.
Preparing patients to be involved

• Inform patients about shared decision making

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• Redefine perceptions of a good patient and reassure patients that participation will not result in retribution

• Promote social acceptability of this role

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Health literacy: Skills and abilities

- Three-level hierarchy of health literacy skill development\textsuperscript{10}

\begin{itemize}
\item Functional health literacy
\item Communicative health literacy
\item Critical health literacy
\end{itemize}
Health literacy: Skills and abilities

- Three-level hierarchy of health literacy skill development

  - **Functional health literacy**
    
    Basic-level skills that are sufficient for individuals to obtain health information, and apply knowledge to a range of prescribed activities.

  - **Communicative health literacy**

  - **Critical health literacy**
Health literacy: Skills and abilities

- Three-level hierarchy of health literacy skill development

  More advanced literacy skills which can be used to participate actively in everyday situations, extract health information and derive meaning from different forms of health communication, and apply this to changing circumstances to make decisions about their health.
Health literacy: Skills and abilities

- Three-level hierarchy of health literacy skill development

  10. Functional health literacy

  2. Communicative health literacy

  3. Critical health literacy

Most advanced cognitive and social skills needed to critically assess the applicability of health information to personal situations or its reliability, and obtain and use information to exert greater control over life events and situations.
Health literacy: an asset approach

- At different times in the shared decision-making process, all levels of health literacy skills (functional, communicative and critical) are required for engagement with healthcare professionals.\(^{11,12}\)
Health literacy: an asset approach

- Health literacy skills for shared decision-making\textsuperscript{11,12}

- Functional health literacy
- Communicative health literacy
- Critical health literacy

\textit{e.g.} describing symptoms, asking clarification questions, reading a decision aid

Empowerment & Decision-making
Health literacy: an asset approach

- Health literacy skills for shared decision-making\(^{11,12}\)

- Functional health literacy
- Communicative health literacy
- Critical health literacy

e.g. asking about options, benefits and harms

Empowerment & Decision-making
Health literacy: an asset approach

- Health literacy skills for shared decision-making

Empowerment & Decision-making

- Functional health literacy
- Communicative health literacy
- Critical health literacy

E.g. integrating knowledge with preferences to make an informed decision
Health literacy: an asset approach

- Health literacy skills for shared decision-making can be improved through education and training
  - TAFE Living Literacy Program$^{13,14}$
  - Informed Health Choices$^{15}$
  - Parenting Plus
  - SUCCESS
## Platforms for developing health literacy skills

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<th>Adult education</th>
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<th>Digital platforms</th>
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Summary

References


References


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