Health literacy – a resource for improving health outcomes and reducing health inequalities

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Deakin University, Melbourne

Overview

• Relevant background
• Health service responsiveness
• Measurement of health literacy
• Ophelia Victoria
• Health Literacy Response Framework
The concept of health literacy exists:
• In academic journals
• In the media
• In health policy
But how does it exist in a person’s life?
• What is health literacy?
• How can it be operationalised?
• Can it be used to drive system-wide health improvements?
• Can it be used to reduce health inequities?

Brief history of ‘health literacy’
1974 - term health literacy first applied
1980s - debates on the definition of health literacy. Association studies between literacy and health outcomes
1990s - first generation health literacy measurement tools focused on literacy and numeracy. Institutionally endorsed definitions
2000s – causal models, intervention development and early intervention trials. Several systematic reviews
2007-2015 - sixfold increase in ‘health literacy papers’. New multi-dimensional tools. Social aspects of health literacy more recognised

Two approaches to thinking about health literacy
1. Narrower approach:
   • research oriented
   • literal concept of ‘literacy’
   • focused on precise definition of the construct and distinguishing it from other constructs (e.g. patient activation)
2. Broader approach:
   • practically oriented
   • metaphorical concept of ‘literacy’ (like computer literacy or financial literacy)
   • focused on being inclusive and identifying all the factors required for people to make effective decisions about health

Health literacy: several definitions
• The cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health (World Health Organization)
• The capacity of an individual to obtain, interpret and understand basic health information and services in ways that are health enhancing (UK National Consumers Council)
• An individual’s overall capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions (UK Institute of Medicine)
• The ability to make sound health decisions in the context of everyday life ... (Kickbusch, 2001)
• People’s competencies to access, understand, appraise and apply information to make health decisions (Sorensen 2011)

Health literacy
Health literacy brings together many concepts that relate to what people need to make effective decisions about health for themselves, their families and their communities.
Health literacy is...
the characteristics of the person + the resources and supports they need

Every one will be different in what they need and what they have....

Health literacy responsiveness is....
the way in which healthcare services make accessible to people with varying health literacy strengths and limitations (accessible = approachable, acceptable, available, affordable, appropriate)
Health service responsiveness and access to healthcare

People engage with services by:

Approaching a health service

Receiving a service

Service is responsive to needs

Fully engages with providers/fully understands own health needs

Health literacy responsiveness is:

Accessible to people with varying health literacy strengths and limitations.

Examples of health literacy barriers:

People not accessing the service

• Little knowledge about entitlement to service
• Lack of confidence

Large numbers of clients ‘do not attend’

• Limited knowledge of how the service works
• Difficulty explaining needs to intake workers

Clients drop out; outcomes not achieved

• Services don’t tailor what they do to individual patients’ learning needs or styles

Services are not developed to engage and fully understand needs

• Providers unaware that patients are not able to put knowledge into practice — may lead to frustration and lack of trust

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Low health literacy has been associated with…….

- increased hospital admissions and readmissions
- poorer medication adherence, increased adverse medication events
- less participation in prevention activities
- higher prevalence of health risk factors
- poorer self-management of chronic diseases and poorer disease outcomes
- less effective communication with health care professionals
- increased health care costs
- lower functional status
- increased mortality

Extensive systematic review:

but…….

- Numerous studies had methodological weaknesses including inadequate consideration of possible confounders
- Most use the REALM, TOFHLA or NVS, ‘unidimensional’ measures

Rapid Estimate of Adult Literacy in Medicine: REALM

<table>
<thead>
<tr>
<th>List 1</th>
<th>List 2</th>
<th>List 3</th>
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<tbody>
<tr>
<td>felt</td>
<td>fatigue</td>
<td>urticaria</td>
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<td>flu</td>
<td>派出</td>
<td>menstruation</td>
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<td>pale</td>
<td>disease</td>
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<td>dose</td>
<td>infection</td>
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<td>eye</td>
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<td>stress</td>
<td>behaviour</td>
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<td>answer</td>
<td>prescription</td>
<td>occupation</td>
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<td>nerve</td>
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<td>games</td>
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Newest vital sign (NVS)

**READ TO SUBJECT:** This information is on the back of a container of a pint of ice cream.

**QUESTIONS**

1. If you eat the entire container, how many calories will you eat?

**Answer:** 1,000

Test of Functional Health Literacy in Adults: TOFHLA

**Numeracy (17 items)**

Abbecefbin VK Tablets 250mg 50:
Take ONE tablet by mouth four times a day

Mr Ian Garfield 91 Potts 16/9/64 or Michael Lubin FFA6185/58
$11.53

Q1. If you take your first tablet at 7:00am, when should you take the next one? 

Q2. And the next one after that?
Health literacy is...

the characteristics of the person + the resources and supports they need to
...information and services to make decisions about their health and the health of their family and community

<table>
<thead>
<tr>
<th>Access</th>
<th>Understand</th>
<th>Appraise</th>
<th>Use</th>
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Some new multidimensional approaches to health literacy measurement

- Health Literacy Questionnaire (HLQ)
  - Western culture / developed countries (Australia)
- Information and Support for Health Actions Questionnaire (ISHA-Q)
  - communal cultures/ LMICs (Thailand)
- European Health Literacy Survey (HLS-EU)
  - measurement of populations
- National Health Literacy Assessment for Children
  - Taiwan
- Functional, Communicative and Critical HL in diabetes scale; All Aspects of Health Literacy Scale (AALHS)

Grounded development of questionnaires:

Concept mapping

Structured process that captures the local wisdom of patients, practitioners and policy makers

Seeding statement:

Thinking about your experiences in trying to look after your health (or that of your family), what does a person need to be able to get and use all of the information they need?

1. Brainstorming session
2. Sorting and rating of statements
3. Multivariate analysis
4. Interpretation of maps

A multi-dimensional health literacy tool

Example Questions:

1. Feeling understood and supported by healthcare providers
   I can rely on at least one healthcare provider
2. Having sufficient information to manage my health
   I am sure I have all the information I need to manage my health effectively
3. Actively managing my health
   I spend quite a lot of time actively managing my health
4. Social support for health
   I have at least one person who can come to medical appointments with me
5. Appraisal of health information
   When I see new information about health, I check on whether it is true or not
6. Ability to actively engage with healthcare providers
   Discuss things with healthcare providers until you understand all you need to
7. Navigating the healthcare system
   Decide which healthcare provider you need to see
8. Ability to find good health information
   Get health information in words you understand
9. Understand health information well enough to know what to do
   Understand what healthcare providers are asking you to

This paper describes the development and validation of the HLQ

To access this paper:

http://www.biomedcentral.com/1471-2458/13/658
The HLQ has nine individual scales (each scored separately):

<table>
<thead>
<tr>
<th>Scale</th>
<th>Description</th>
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Profiles can be used to:
Explore individual client strengths and limitations.

Example of a group of clients (using cluster analysis to group people with similar health literacy profiles together)

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Provides a profile of a person’s health literacy strengths and needs.

HLQ data can be combined with demographic and interview data to develop a ‘vignette’ about what it’s like to live with that health literacy profile.

**Simon** is a 51 year old man who works as a painter for a large company. He is finding the work harder as he gets older, mostly because of the back pain he has had for years. He drinks and smokes a lot and is starting to lose his breath when climbing ladders. He feels quite down about his worsening health but just sees it as part of getting older. His father died of heart disease at age 60, so Simon half expects the same thing to happen to him. He’s aware that he should take steps to stop smoking and drinking (scale 3) but doesn’t know where to go to get help (scale 7). When he tried to cut down last year, all his mates just laughed at him (scale 4). He doesn’t really trust doctors anyway (scale 1); he’s been telling them about his back pain for years but they haven’t done anything about it.

What is the Ophelia Approach?

- A way of identifying health literacy needs, and then developing and testing potential solutions.
- Allows easy application of evidence-based health promotion approaches to the field of health literacy.

Ophelia means Optimizing Health Literacy and Access to health information and services.

Health literacy intervention development

- **Problem**
  - *I can not* go to the literature to get Health Literacy interventions.
  - There is nothing there that will fit my clinic/ community/ culture.
- **Realisation**
  - There is nothing new in health literacy, it is what GREAT frontline practitioners do each day.
- **Solution**
  - Use data from ‘usual’ patients.
  - Work with the best frontline practitioners and managers and capture their experiential knowledge and wisdom.
Simon is a 51 year old man who works as a painter for a large company. He is finding the work more difficult as he gets older, mostly because of the back pain he has had for years. He drinks and smokes a lot and has noticed that he’s starting to lose his breath when climbing ladders. He feels quite depressed about his worsening health but just sees it as part of getting older. His father died of heart disease at age 60, so Simon half expects the same thing to happen to him. He’s aware that he should take steps to stop smoking and drinking (scale 3) but doesn’t know where to go to for help (scale 7). When he tried to cut down last year, all his mates just laughed at him (scale 4). He doesn’t really trust doctors anyway (scale 3), he’s been telling them about his back pain for years, but they haven’t done anything.

15% of the people coming to your service have a health literacy needs profile like this. In what way could your organisation meet these needs?

**Advantages of working with practitioners**

- Years of experience and tacit knowledge are important resources
- Knowledge of local situations
- Knowledge of people
- Able to respond to issues not covered by the literature
- Likely to be implementable
- Don’t need to achieve subsequent buy-in
- Don’t need to convince them it’s a good idea… it’s their idea!

**Ophelia - aims**

- Ophelia aims to improve health outcomes and reduce health inequalities for people with long-term conditions, by
  - Empowering health/community services and service providers to optimise the health literacy of their clients and community, by
  - Improving their responsiveness to clients with varying health literacy strengths and needs

**Ophelia Victoria - methods**

- Healthcare services from 4 diverse regions invited to apply:
  - Community health centres, municipal councils, home nursing and hospital admission risk programs (9 sites in total)
  - n=813 clients from nine sites provided HLQ and demographic data
- Semi-structured interviews with 4-6 clients at each site
  - Stories behind the HLQ scores to inform vignettes
  - 3-hour workshops with clinicians and managers at each site
### Focus of intervention

#### Examples

<table>
<thead>
<tr>
<th>Focus of intervention</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Client</strong></td>
<td>Improving skills in appraisal of information (e.g., computer courses in a disadvantaged area)</td>
</tr>
<tr>
<td></td>
<td>Providing resources for clients to better engage with doctors</td>
</tr>
<tr>
<td><strong>Practitioner</strong></td>
<td>Enhanced skills for education of clients (e.g., identification of clients’ preferred learning styles)</td>
</tr>
<tr>
<td></td>
<td>Strategies to help clients operationalise care plans (e.g., teaching)</td>
</tr>
<tr>
<td><strong>Organisation</strong></td>
<td>Service access policies (e.g., directing clients with chronic disease from ‘one-off’ visits to an ongoing model of care)</td>
</tr>
<tr>
<td></td>
<td>Nurse ‘care coordination’ in rural community health centre</td>
</tr>
<tr>
<td></td>
<td>Training volunteers and peers to deliver health literacy messages (e.g., delivered by volunteers in rural programs)</td>
</tr>
<tr>
<td><strong>Inter-agency</strong></td>
<td>Engaging other organisations for mutual benefit (e.g., training members of the local Country Women’s Association as ‘health coaches’ for older community members to support falls prevention)</td>
</tr>
</tbody>
</table>

### Evaluation of Ophelia Victoria projects

- **Examples include:**
  - Relevant scales of the HLQ (pre and post intervention)
  - Interviews with clients about e.g. the impact of the intervention in their everyday life
  - Interviews with clinicians about the way in which they communicate with or understand clients, or other changes to their practice
  - Disease-specific questionnaires related to knowledge or self-management skills
  - Number and type of service referrals

### Evaluation of Ophelia Victoria projects occurred across multiple ‘levels’

- **What changes occurred:**
  - For the clients?
  - At individual clinician level?
  - At an organisational level?
  - Were there any ‘ripple’ effects that could be measured more widely in the community?

### Results – intervention ideas

- Cluster analysis revealed a wide range of health literacy profiles for each site
- Over 200 intervention ideas generated at feedback workshops
- Following the workshops, intervention ideas were:
  - Refined collaboratively using modified program logic models
  - Processes were pilot tested using quality cycles
  - Interventions ‘rolled out’ more broadly within each service

### Evaluation of Ophelia Victoria projects

**Evaluation of Ophelia Victoria projects**

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**Intervention to train volunteers as health mentors in their local communities + develop supporting resources (questions for good health, video, links to reputable websites)**

<table>
<thead>
<tr>
<th>HLQ data (10 volunteers and 13 clients agreed to evaluation)</th>
<th>Have sufficient information to manage my health (scale 2) Mean (SD)</th>
<th>Appraisal of health information (scale 5) Mean (SD)</th>
<th>Actively engage with healthcare providers (scale 6) Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre intervention</td>
<td>2.95 (0.49)</td>
<td>2.89 (0.49)</td>
<td>4.03 (0.50)</td>
</tr>
<tr>
<td>Post intervention</td>
<td>3.22 (0.60)</td>
<td>3.07 (0.70)</td>
<td>4.34 (0.61)</td>
</tr>
<tr>
<td>Effect size for difference (95% CI)</td>
<td>(0.56)</td>
<td>0.52</td>
<td>0.56</td>
</tr>
</tbody>
</table>
Interviews with mentors and clients were also conducted

- Community members = multiple stories of positive outcomes reported, e.g. asking more questions and feeling more prepared for GP visits.
- Volunteers = responses indicated a sense of feeling useful, alongside pride and achievement from participating in a health promoting project.
- Responses indicated a ripple effect in terms of clinicians, volunteers and clients spreading the study’s message within existing circles.

What next?

- Overall Ophelia evaluation – what were the organisational impacts?
- Realist analysis – what worked for whom under what circumstances?
- Development of a Health Literacy Response Framework

Health Literacy Response Framework

- Patient level responses

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subtheme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Build trust</td>
<td>Responsibility to need; ensure consideration is given to duration of care, consistency of contact person; reliability, involvement of family/carers; respect for the patient; amount of time allowed for contacts; delivering something of use to consumer</td>
</tr>
<tr>
<td>Provide patient-centered care</td>
<td>Focus on patient needs; flexible mode of service delivery – out of hours, outreach, telephone, internet etc; service enabled to respond, distribution of barriers to engagement</td>
</tr>
<tr>
<td>Coordinate care</td>
<td>Facilitating access and links with GP; coordination of care between healthcare providers</td>
</tr>
</tbody>
</table>

Development of the Health Literacy Response Framework (HL-RF)

- Local stakeholders generate insights into:
  1. The health literacy needs of patients, and;
  2. Potential strategies for optimising health literacy and improving organisational responsiveness

- Thematic analysis of intervention ideas, and matching of themes to health literacy needs

- Identification of mechanisms by which interventions influence health literacy

- Identification of provider, organisational and higher order requirements

Health Literacy Response Framework

- Patient level responses

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<td>Care coordination</td>
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</tbody>
</table>
Health Literacy Response Framework

- Practitioner level responses

**Practitioner level strategies to support and build capacity of practitioners / staff**

<table>
<thead>
<tr>
<th>Professional Development</th>
<th>Building networks and relationships</th>
<th>Practice guidelines</th>
<th>Tools, aids &amp; resources</th>
<th>Management &amp; monitoring</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Building capacity and confidence</td>
<td>- Organising and facilitating peer support groups and share learning</td>
<td>- Providing practice guidelines and resources</td>
<td>- Providing tools, aids &amp; resources</td>
<td>- Managing and monitoring performance</td>
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Health Literacy Response Framework

- Organisational level responses

**Organisational level strategies to influence the culture, and improve the accessibility, efficiency and equity of services**

<table>
<thead>
<tr>
<th>Marketing</th>
<th>Partnerships with local services</th>
<th>Services offered</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Implementing changes to improve access to services</td>
<td>- Developing partnerships with local services</td>
<td>- Providing health literacy services</td>
</tr>
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</table>

Health Literacy Response Framework

- Interagency level responses

**Regional/State level strategies to optimise service coverage and integration**

<table>
<thead>
<tr>
<th>Service integration</th>
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<tbody>
<tr>
<td>- Developing a service directory, including the locations of community services,</td>
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</table>

Health Literacy Response Framework

**Individual level strategies to improve health literacy and engagement**

<table>
<thead>
<tr>
<th>Ophelia website</th>
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<tbody>
<tr>
<td>- Ophelia website, including the latest news and events,</td>
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**Ophelia website**

- www.ophelia.net.au
- Ophelia website, including the latest news and events, resources, and tools for improving health literacy.
Ophelia Toolkit

A step-by-step guide to identify the health literacy needs of a local community, and to develop and implement responses to those needs.

Includes a range of practical tools and resources that can be used at each stage of the process.

Thank you!

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