HEALTH LITERACY AND SDM

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WHAT WE KNOW

WHAT WE DON’T KNOW
WHAT WE KNOW
DEFINITIONS OF HEALTH LITERACY

- Health literacy can be defined in different ways and can refer to the individual or health system/environment.

- Individual level:

  ‘The capacity to obtain, interpret and understand basic health information and services and the competence to use such information and services to enhance health’

  (US Healthy People 2010, USDHHS 2000)
WHAT IS HEALTH LITERACY?

Broader 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….it means more than being able to read pamphlets….By improving people’s access to health information and their capacity to use it effectively, health literacy is critical to empowerment.’

(WHO 1998)

- **Functional HL**: Reading, writing, numeracy, oral skills
- **Communicative/interactive HL**: Advanced cognitive and social skills
- **Critical HL**: Ability to analyse and act on information

**THEORETICAL FRAMEWORK**
A MODEL OF HEALTH LITERACY

SDM is the pinnacle of health literacy

- SDM
- Critical HL
- Communicative/interactive HL
- Functional HL
Low health literacy is common

- National populations surveys (US, UK and Australia) show between 36-48% of adults have ‘limited’ / ‘inadequate’ health literacy (Kutner et al 2006; OECD 2005, ABS 2006).

- Low numeracy is even more common: 60% ‘inadequate’ numeracy (ABS 2006)

- High % adults struggle to understand routine / ‘every day’ written information
Low health literacy linked with poor health outcomes independent of other risk factors:

- Higher rates of chronic illness (e.g. hypertension, heart disease, diabetes, obesity)
- Higher rates of mortality (any cause)
- Higher hospitalisation rates and use of emergency services
- Lower rates of preventive services such as screening
- Poorer self management skills
- Greater medication errors
- Lower levels of knowledge about disease
- Lower ratings of doctor-patient communication

(AHRQ Systematic reviews: DeWalt et al 2004; Berkman et al 2011)
Important to ensure SDM can be accessed by adults with lower health literacy
1. Ethically – we should seek to ensure equal access to SDM – not systematically exclude groups

2. Risk of increasing already present inequalities:

   - Health literate as information rich with access to choice
   - Lower health literate as information poor & little access to choice

3. Lower health literacy patients are over-represented in the health system – poorer health and health outcomes

4. Clinicians report they find communication challenging with lower literacy patients, cite as a barrier to SDM
1. Ethically – we should seek to ensure equal access to PtDAs – not systematically exclude groups.

2. Risk of increasing already present inequalities: 
   - Lower health literate as information poor & little access to choice

3. Lower health literate patients are over-represented in the health system – poorer health and health outcomes.

4. Clinicians report they find communication challenging with lower literacy patients cite as a barrier to SDM (eg Stacey et al 2011).
WHAT EVIDENCE EXISTS?

- As part of the IPDAS guidelines 2011-2012 update we reviewed the health literacy literature relevant to PtDAs

  Review Group: Kirsten McCaffery, Stacey Sheridan, Don Nutbeam (co-leads) Sian Smith, Margaret-Holmes Rovner, David Rovner, Karen Kelly-Blake, Marla Clayman, Mike Wolf (team members)
IPDAS Guidelines Update 2012

REVIEW 1

General Health Literacy / Literacy Literature relevant to PtDAs

What is the relationship between health literacy and numeracy and decision making outcomes and interventions?

REVIEW 2

Specific Patient Decision Aid Literature

To what extent do existing PtDAs and PtDA trials address issues of health literacy?
What is the relationship between health literacy and numeracy and decision making outcomes and interventions?
Two questions:

1. What is the effect of HL and numeracy on specified decision making outcomes?
   - Health knowledge/ understanding/ comprehension incl accurate risk perception
   - Values clarification
   - Patient involvement and communication

2. What is known about the effects of interventions to mitigate the impact of HL or numeracy?
Lower HL strongly associated with lower patient understanding/knowledge in 14/16 studies (Dewalt et al 2004).

Interventions studies suggested strategies to improve understanding (14 studies relevant to PtDAs) (Berkman et al 2011; Sheridan et al 2011)

### Practical design strategies to improve understanding

- Present essential information first (Peters et al 2007)
- Present numerical information in tables or pictographs (Galesic et al 2009; Garcia-Retamero 2009)
- Present numerical information so the higher number is better (Peters et al 2007)
- Present numerical information with a consistent denominator (Garcia-Retamero 2009)
- Use natural frequencies (Galesic et al 2009b)
VCE/ patient involvement/ communication: 17 cross sectional studies, 1 intervention study.

- Patients with lower health literacy had:
  - Higher decisional uncertainty and regret,
  - Less involvement in DM and less PCC
  - Asked less questions (Qs asked clarifying Qs)

- 1 intervention study showed reduced decisional uncertainty using patient videos (Volandes et al 2009)
1. Systematically reviewed PtDAs published in latest Cochrane review (Stacey et al 2011) updated to include articles published to the end of 2010.

2. PtDAs scored against a pre-specified criteria (based on IPDAS 2006 HL recommendations)

REVIEW 2

Specific Patient Decision Aid Literature

To what extent do existing PtDAs and PtDA trials address issues of health literacy?
RESULTS

Out of 97 PtDA trials

- 5 reported a reading level at the recommended age (≤ grade 8)
- 2 followed health literacy criteria but did not state which
- 7 recruited ‘lower literacy’ patients based on educational level
- Multi media used by many but difficult to evaluate whether they addressed health literacy
- Only 3 RCTs of PtDAs among lower health literacy / education adults
  - 2 showed increased knowledge in lower education adults (Trevena et al 2008; Smith et al 2010)
  - 1 showed increased informed choice (Smith et al 2010)
  - 2 show lower decisional conflict (Volk et al 2008; Smith et al 2010)
SUMMARY

- Very little attention paid to health literacy
- But where health literacy was addressed – results encouraging with improvements in knowledge, informed choice and decisional conflict

NOTE: Review only focussed on PtDAs not SDM more broadly
OTHER RELEVANT LITERATURE

  - Low HL patients don’t understand what SDM is
  - Not confident to ask questions/ be involved
- Legare et al 2011: perceived behavioural control significant mediator of intentions to engage SDM in primary care for lower literacy women.

- Broader HL literature varied success in improving HL. Successful interventions tended to have be (Sheridan et al 2011):
  - Multifaceted, intensive (eg. extended telephone follow-up)
  - Theory based
  - Pilot testing
  - Emphasis on skill-building
  - Delivery by HCPs better than non HCPs
WHAT WE DON’T KNOW
WHAT WE DON’T KNOW

- Values clarification processes in PtDAs or SDM
- Supporting communication and involvement in decision making/ implementing shared decisions
- Little about QPL interventions despite large body of literature
- Few intervention studies with only 3 PtDA RCTs (none measured HL directly).
- How to implement SDM interventions in lower literacy patients in primary care or other health settings
SUMMARY

We know

- What HL is
- How to measure it*
- How to prepare health information for lower HL patients
- Have some helpful evidence on how to improve outcomes for low HL pts generally
  - Area of considerable debate

We DON’T know

- How to best support values clarification
- How to improve Dr-pt communication for SDM
- How to increase low pt confidence/ SE in SDM
- How to implement SDM among low HL pts effectively
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• Develop Materials [http://www.cdc.gov/healthliteracy/DevelopMaterials/]
  http://www.cdc.gov/healthliteracy/developmaterials/guidancestandards.html

• Health Literacy Universal Precautions Toolkit. AHRQ Publication No. 10-0046-EF

• DeWalt D, Callahan L, Hawk V, Broucksou K, Hink A, Rudd R, Brach C: Health Literacy
  Universal Precautions Toolkit. (Prepared by North Carolina Network Consortium, Rockville, MD:

• Federal plain language guidelines

• Health literacy studies: assessing and developing health materials
  [http://www.hsph.harvard.edu/healthliteracy/practice/innovative-actions/index.html]

• Doak CC, Doak LG, Root JH: Teaching patients with low literacy skills, 2nd edn.