Aims of Workshop
About 40% of the world population has problems with access to, understanding of, and applying information about their health and health care. This is called Health illiteracy and results in high health backlogs.

In this workshop we will illuminate on the problems that patients and their caregivers experience in dealing with health illiteracy. We will discuss groups at risk, highlight low incontinence literacy and discuss patient’s interest in use of electronic applications. We will offer tools to help you better recognize such patients and give examples of adjusted patient information materials to ensure better communication and optimal information transferral. We welcome discussion of experiences of delegates internationally.

Interactive session
In this part attendants are asked to share their experiences, and examples of problems, regarding low health or incontinence literacy. They are also invited to share their own initiatives or ideas on how to address the problem.

Learning Objectives
- Explain health illiteracy and the problems this may cause.
- Review risks for low health literacy and highlight evidence about low incontinence literacy.
- Discuss barriers to improving incontinence literacy.
- Provide tools to better recognize the patients with low health literacy.
- Show examples of adjusted patient information materials to ensure better communication and optimal information transferral.
- Discuss experiences and approaches of delegates internationally to improve health/incontinence literacy.

Learning Outcomes
After this workshop participants are able to:
- Explain health/incontinence illiteracy and its consequences.
- Better identify patients with low health literacy.
- Identify approaches to better inform patients and caregivers and promote communication with healthcare providers.

Target Audience
Any healthcare professional who works with or does research with patients

Advanced/Basic
Basic

Conditions for Learning
This is an interactive course- examples and experiences provided by speakers and attendants will be used for the discussions
**Suggested Reading**


**Other Supporting Documents, Teaching Tools, Patient Education etc**

Here is a link to some patient and caregiver information that is developed for raising literacy about incontinence that is offered on the ICS webpage library:


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**M.R. van Balken**

What is Health Illiteracy? Is it the same as not being able to read? Why is it a problem?

In this first part of the workshop background information is given and questions like above are being answered. Think about items as prevalence, how it differs worldwide, why it leads to extra costs and what it means for patients. Special attention will be paid on how to recognize patients with low health literacy patients as they tend not to reveal themselves. This calls for better awareness amongst healthcare providers and an active approach to deal with the problem.

**Donna Z. Bliss**

What are the known groups at risk for low health literacy in general and what is some evidence about low incontinence literacy and potential variations in profiles?

This part of the workshop will review this information and discuss barriers identified by healthcare providers, patients, and caregivers to communication about incontinence thereby reducing opportunities for raising incontinence literacy. The potential role and concerns about for mobile/electronic applications/resources to improve incontinence literacy will also be addressed.

**F.W.M. Schlatmann**

How can we improve information transferal to patients with low health literacy?

In the third part of this Workshop we will explain different ways and materials for informing and diagnosing patients. As example: the alternative ‘Visual Prostate Symptom Score’ (VPSS) for current IPSS. Or information leaflets with images instead of only text (recently implemented by the Dutch Association of Urology). Also, the read-aloud-function on websites and spoken animations will be discussed. Let’s make things better!
Health Literacy for Incontinence
What Is Known
Donna Z. Bliss, PhD, RN, FGSA, FAAN
Professor & Professor of Nursing
Research
University of Minnesota School of Nursing
Minneapolis, MN

Donna Bliss
Affiliations to disclose:
- Consulting agreement for research with Donor and
titans
- Travel expenses and honorarium for conference
presentation from Hartmann
- Subcontract of NIH grant of Innovative Design Labs for an
educational simulation program

Funding for speaker to attend
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☐ Foundation/industry funded
☐ Sponsored by

Health Literacy
US (NH and ICDM):
- Access and navigate health information and healthcare
system and seek care
- Communicate with healthcare provider
- Understand info and make choices
- Manage chronic health conditions
- Engage in symptom self-management

Europe (WHO):
- Health care + disease prevention + health promotio
- Ageing (65+) of health literacy: The third
- Older adults: 2012 National core competencies, multi-

Low Health Literacy
- Overall 12%-50% of adults (varies by country)
- Better in Netherlands, worse in Bulgaria, Spain, & Austria
- Groups at Risk
  - Older people (>75yrs)
  - Non-White racial groups, minority immigrants
  - English not first language
  - Income s poverty level, low SES
  - Less education (< High school)
  - Chronic diseases
- Surveys in US, Europe, Australia

Low Health Literacy Negative Effects
- Self-reported health status — worse
- Increased rates of non-communicable diseases
  - cancer, diabetes, heart, and respiratory disease
- Less communication with providers
- More hospitalizations
- Increased healthcare costs
- Cost to US economy = $106 - $236 billion USD annually
  (2010)
- Feel stigmatized

Babbie, S. National Assessment of Adult Literacy, NAL. 2003, Gall &
Report to the nation on literacy in the 21st Century. National Adult Literacy
Survey, 2005. University of Minnesota School of Nursing, 2005

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Examples – Low Incontinence Literacy

- Women with pelvic floor (PF) disorders (UI and/or POP) (n=36) (Scheer et al., Menopause & Women's Health, 2014)
  - Poor understanding of their PF condition, despite high general health literacy scores
  - Low recall of PF diagnosis and treatment plan
  - Aged 62-94 years, 61% White, 39% high school
- Survey of women with AI from US OB/Gyn clinic (n=161)
  - 47% “did not know anything,” 36% “knew a little” about self-management of AI before seeing a clinician (Kaufman et al., ICS, 2014)
- 1/3 church group (n=145) desired more info about incontinence and its treatment (M & F, aged 21-90 yrs) (Kaufman et al., ICS, 2014)

Fi Conservative Management

**Initial Interventions**
- Discussion of options, patient’s goals of management
- Education of patient and/or caregiver
- Diet and eating pattern modifications, dietary fibre supplements
- Medications (Opromedics)
- Bowel habit training
- Transanal irrigation
- Incontinence absorbent products
- Practical advice for coping (locating toilets, cleansing kits, etc)

**Secondary Interventions**
- PFMT
- Biofeedback
- Incontinence containment products such as anal plug, insert, etc.

Assessing Incontinence Literacy Needs of Carers of Individuals with AD

- n = 48
- 75% female
- Age: 54 (14) yrs (mean [sd])
- 71% a high school

- Race/Ethnicity
  - 52% White, non-Hispanic
  - 48% minority
  - 0% Black
  - 6% Hispanic
  - 10% White, not Hispanic

- Types of Caregivers
  - 43% spouses
  - 31% children (daughters)
  - 14% other relative
  - 10% friends

- Care Recipients
  - 68% incontinent
  - 33% UI only
  - 25% UI+FP
  - 62% female
  - Age: 80 (9) yrs

Health Literacy Needs of Caregivers

- Family/friend caregivers are often essential participants in a patient’s plan of care
- Caregivers of cancer patients
  - Difficulty learning clinical information
  - Unable to interpret details of care
  - Receive too little or too much information
  - Dissatisfied with the communication & abrupt manner of clinicians (Brewer et al., Patient Education Counseling, 2000)

Incontinence Literacy Needs

**Knowledge**
- Why/how incontinence occurs in AD?
- “Adult” terms for incontinence, UI, and skin damage
- Management options other than pads
- Guide to absorbent and skin care products
- Questions to ask a nursing home care team
- Wives feel more confident/knowledgeable than husbands
- Don’t know what info on internet to believe
- Non-relative/friend caregiver often not included/consulted by clinician
Evidence of low incontinence literacy

- Patients & Caregivers
- Need to promote many aspects of incontinence literacy
  - Multidisciplinary involvement, policy
  - Effective approaches evolving
  - New technologies offer variety of tools, strategies
  - Assess impact on outcomes
Examples of adapted materials are:

1. Visual Prostate Symptom Score
2. Leaflets with photo stories
3. Read-aloud-function on websites
4. Information leaflets with mainly images

1. Visual Prostate Symptom Score

Statistically significant correlation between the VPSS and IPSS

Validated in:
- San Francisco
- France
- Turkey
- Nepal
- India
- Africa
- The Netherlands
STUDY 1
Experimental study on the effects on knowledge and behavioural intentions.

- Group 1: photo story
- Group 2: traditional brochure
- Group 3: control, no brochure

Results:
- Photo stories result in:
  - Higher levels of knowledge
  - No effect on behaviour
  - Higher intention to talk to a doctor about their problem

STUDY 2
Interview study: majority of Dutch participants had a clear preference for the photo stories
- Motivated to read it
- Was comprehensible
- Expected more behavioural and cognitive effects


Koops van 't Jagt R, et al. Using photo stories to support doctor-patient communication. Three studies into a communicative health literacy intervention for older adults. Resubmitted to Journal of Health Communication on April 13th, 2018
4. Information leaflets with mainly images
Video-Based Educational Tool Improves Patient Comprehension of Common Prostate Health Terminology


STAND UP

CORELESS COMMUNICATION TECHNIQUES

WANG IS RING
Share your story.

ILLITERATE'S EVERYWHERE

BE AWARE

SERIOUS IMPACT!

LEARN TO ADAPT

if we didn't think we were going to change the world, we wouldn't be here.