

| Start | End | Topic | Speakers |
|-------|-------|--|--------------------|
| 13:30 | 13:35 | Welcome & Introduction | Michael van Balken |
| 13:35 | 13:50 | What is Health Illiteracy? Is it the same as not being able to read? Why is it a problem? | Michael van Balken |
| 13:50 | 14:05 | 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? | Donna Bliss |
| 14:05 | 14:15 | How can we improve information transferral to patients with low health literacy? | Florine Schlatmann |
| 14:15 | 14:30 | Discussion | |

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

Anger, JT, Lee, UJ, Mittal, BM, Pollard, ME, Tarnay, CM, Maliski, S, Rogers, RG. Health Literacy and Disease Understanding Among Aging Women With Pelvic Floor Disorders. *Female Pelvic Med Reconstr Surg.* 2012;18: 340Y343

Asklund I, Nyström E, Sjöström M, Umefjord G, Stenlund H, & Samuelsson E. Mobile app for treatment of stress urinary incontinence: A randomized controlled trial. *Neurology and Urodynamics.* 2016; DOI: 10.1002/nau.23116

Bliss, D.Z., Rolnick, C., Jackson, J., Arntson, C., Mullins, B.A, Hepburn, K. (2013). Health literacy needs related to incontinence and skin damage among family and friend caregivers of individuals with dementia. *Journal of Wound, Ostomy, and Continence Nursing,* 40, 515-523.

Mullins, J., Bliss, D.Z., Rolnick, C., Henre, C.A., Jackson, J. (2016). Barriers to Communication with a Healthcare Provider and Health Literacy about Incontinence among Informal Caregivers of Individuals with Dementia. *Journal of Wound, Ostomy, and Continence Nursing,* 43, 539-546.

Rolnick, S.J., Bliss, D.Z., Jackson, J.M. (2013). Healthcare providers' perspectives for promoting communication with family caregivers and patients with dementia about incontinence and skin damage. *Ostomy Wound Management,* 59(4), 62–67.

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:

<https://www.ics.org/Documents/Documents.aspx?FolderID=317>

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

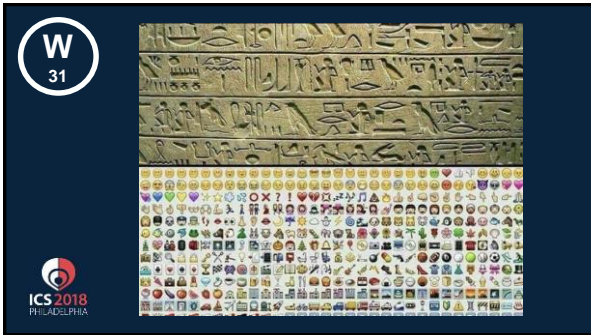
What are the known groups at risk for low health literacy in general and what is some evidence about low incontinence literacy and potential variations in profiles?

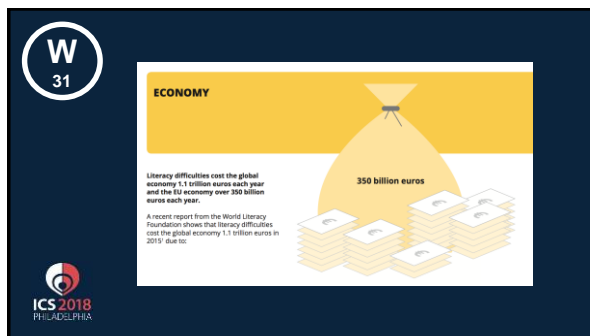
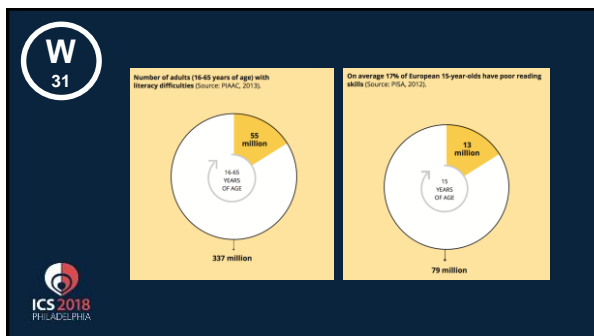
This part of the workshop will review this information and discuss barriers identified by healthcare providers, patients, and caregivers to communication about incontinence thereby reducing opportunities for raising incontinence literacy. The potential role and concerns about for mobile/electronic applications/resources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

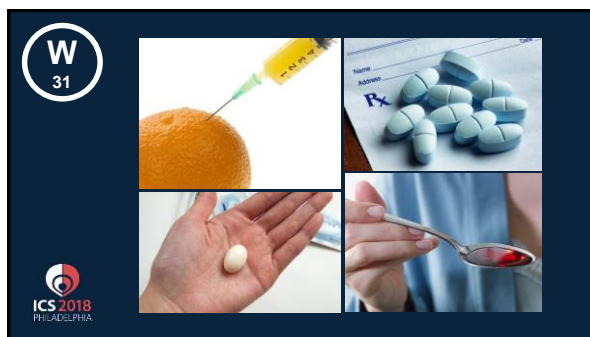
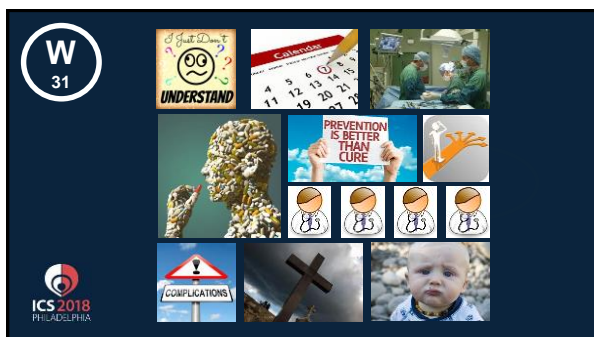




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| | | | |
|--|---|--|---|
| | Lost earnings and limited employability | | Higher spending related to health problems |
| | Lost business productivity | | Higher spending on the justice system due to more crime |
| | Lost wealth creation opportunities for individuals and business | | Higher spending on social services and benefits |
| | Lower technology skills capacity in future | | Higher spending on education due to students falling behind |

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TABOO

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HOW DO I ?

recognise

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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

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Donna Bliss

Affiliations to disclose:

- Consulting agreement for research with **Domlar** and **Hillrom**
- 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:

Self Funded
 Institution (non-industry) funded
 Sponsored by:

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Health Literacy

US (NIH and IOM):

- Access and navigate health information and healthcare system and seek care
- Communicate with a healthcare provider
- Understand info and make choices
- Manage chronic health conditions
- Engage in symptom self-management

(HHS, 2012 <http://www.hhs.gov/ohrt/communication/healthliteracy/>; Institute of Medicine, 2004) <https://www.hog.edu/health1000/ohgpanel/>

Europe (WHO):

- Health care + disease prevention + health promotion (Gibson, 1st of Health Literacy The Solid Facts, WHO, 2013 www.who.int/diabetes/literacy_2013/)

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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
 - Incomes ≤ poverty level, low SES
 - Less education (< High school)
 - Chronic diseases
- Surveys in US, Europe, Australia

(White, S. National Assessment of Adult Literacy, AMA, 2008; Cullif & Bennett, *Orthop Nurs*, 2009; Schaub, 1st et al. Health Literacy: The Solid Facts, WHO, 2013; Palumbo et al., *J Health Org Manage*, 2016; Australia's Health 2012: Adult Literacy and Life Skills Survey, 2008)

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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

(White, S. National Assessment of Adult Literacy, AMA, 2008; Cullif & Bennett, *Orthop Nurs*, 2009; Kukulovich, 1 et al. Health Literacy: The Solid Facts, WHO, 2013; Australia's Health 2012: Adult Literacy and Life Skills Survey, 2008)

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Examples – Low Incontinence Literacy

- Women with pelvic floor (PF) disorders (UI and/or POP) (n=36) (Anger et al., Female Pelvic Med Reconstr Surg, 2012)
 - **Poor understanding** of their PF condition, despite high general health literacy scores
 - **Low recall** of PF diagnosis and treatment plan
 - Aged 42-94 years, 61% White, >90% high school
- Survey of women with AI from US OBGyn clinic (n=161)
 - 47% "did not know anything," 30% "knew a little" about self-management of AI before seeing a clinician (Bliss et al. ICS 2018)
- 1/3 church group (n=145) **desired more info** about incontinence and its treatment (M & F, aged 21-80 yrs) (Gibson, C. JWOCN Abstract, 2016)

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Examples – Low Incontinence Literacy

- Adults with fecal incontinence **lack terms** to describe their problem to clinicians (Patel et al., JWOCN, 2010)
- Use terms for other GI problems – confound dx (e.g., diarrhea, colitis, IBS) (Chakravartan & Norton, Nurs Times 2000; Patel et al., JWOCN, 2010)
- Desire self-management info & practical coping strategies
- Use **trial and error**, borrow strategies from other conditions
- Clinicians perceived as lacking knowledge & dismissing SM strategies and impact of FI (Bliss et al. Incontinence 217; Poldos-McArdle et al. J Rehab Nurs 2012; West J Nurs Res 2008)

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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 (loperamide)
- 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

Bliss et al. Incontinence, 2017

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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 (Bevan et al., Patient Education Counseling 2008)

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Assessing Incontinence Literacy Needs of Carers of Individuals with AD

- n = 48
- Sex: 75% female
- Age = 64 (14) yrs (mean (sd))
71% ≥ high school
- Race/Ethnicity
 - 52% White, not Hispanic
 - 48% minority
 - 10 % Black
 - 6% > 1 race
 - 31% Hispanic
- Types of Caregivers
 - 43% spouses
 - 31% children (daughters)
 - 14% other relative
 - 10% friends
- Care Recipients
 - 58% incontinent
 - 33% UI only
 - 25% UI+FI
 - 62% female
 - Age: 80 (9) yrs

(Bliss et al., JWOCN, 2013) UNIVERSITY OF MINNESOTA School of Nursing

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Incontinence Literacy Needs Knowledge

- Why/how incontinence occurs in AD?
- "Adult" terms for incontinence, sx's, and skin damage
- Management options other than pads
- Guide to absorbent and skin care products
- Questions to ask a nursing home
- 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


(Bliss et al., JWOCN, 2013; Mullins et al., JWOCN, 2016)

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Incontinence Literacy Skills

- "How to"
 - Manage undressing/dressing, modesty issues, skin care
 - Implement techniques/strategies to prevent lesser incontinence
 - Practical strategies for preventing or managing accidents esp. in public
 - kits for cleansing, disposal, toilet locations
 - Encourage cooperation of care recipient
 - Reduce physical burden



(Bliss et al., JWOCN, 2013; Mullins et al., JWOCN, 2016) UNIVERSITY OF MINNESOTA
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Studies of Interventions

- Caregivers of frail elderly trained to perform a toileting intervention
 - reduced UI frequency and volume and perineal dermatitis in 19% of care recipients
(Colling, Urol Nurs 2003)
- UI self-management program improved ICIQ-UI scores, knowledge, attitudes of 17 community Korean women
 - (De Gagne J Int Nurs Sci, 2015)
- Use of a mnemonic (RELIEF) did not assist women to remember treatment plan vs. standard counselling
(Glichowski SB et al., Gaster Gynaecol 2015)


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Studies of Interventions

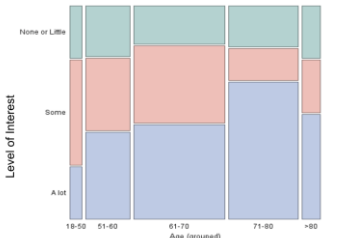
- Internet-based treatment for stress UI (PFMT, CBT) vs mailed hard copy info (n=250)
 - no difference in ICIQ-UI and UI QoL scores of Swedish women
(Sjallbjörk et al. BJU Int 2015)
- Tāt m-app for PFMT self-management of stress UI
 - improved ICIQ-UI and LUTSqol scores of 62 Swedish women vs 62 with delayed Rx
(Sjallbjörk et al. ANU 2017)



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Interest in a future FI app by age of women with FI
(Bliss et al. ICS 2018)

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Summary

- 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

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ADAPTED INFORMATION MATERIALS

informed consent

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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

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1. Visual Prostate Symptom Score

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American Urological Association Symptom Score Index Questionnaire

Having to urinate more frequently, to urinate at night, or to urinate suddenly without the urge of your bladder. The amount of urine you pass will be normal or about normal. (Do not include the amount of urine you pass if you have a urinary tract infection or if you are taking medicine to increase the amount of urine you pass.)

| Patient Name: | Sex: | Circle the number that best applies to you (usually) | | | | |
|-----------------|---|--|---|---|---|---|
| | | 1 | 2 | 3 | 4 | 5 |
| 1. Frequency | How often do you have to urinate during the day? | 0 | 1 | 2 | 3 | 4 |
| 2. Frequency | How often do you have to urinate at night? | 0 | 1 | 2 | 3 | 4 |
| 3. Urgency | How often do you have to urinate suddenly without the urge of your bladder? | 0 | 1 | 2 | 3 | 4 |
| 4. Weak stream | How often do you have a weak stream when you urinate? | 0 | 1 | 2 | 3 | 4 |
| 5. Interference | How often do you have to get up to urinate during the day? | 0 | 1 | 2 | 3 | 4 |
| 6. Interference | How often do you have to get up to urinate at night? | 0 | 1 | 2 | 3 | 4 |

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VPSS (Visual prostate Symptom Score)

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Statistically significant correlation between the VPSS and IPSS

Validated in:

- San Francisco
- France
- Turkey
- Nepal
- India
- Africa
- The Netherlands

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URinControl Geneeskunde

MyWaterworks

Signs & Symptoms Urinary Incontinence

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2. Leaflets with photo stories

Dr. R. Koops van 't Jagt
"Health communication"

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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 studies results 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

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Koops van 't Jagt R, et al. Sweet Temptations: How does reading a foodbrochure about diabetes affect Dutch adults with different levels of literacy? Health Communication 2014;20(2):208-216
 Koops van 't Jagt R, et al. Journal of Health Communication Using photo stories to support doctor-patient communication. These studies into a communicative health literacy intervention for older adults. Submitted to Journal of Health Communication on April 11th, 2018.

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3. Read-aloud-function on websites

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Click to listen!!!

Streaming audio

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4. Information leaflets with mainly images




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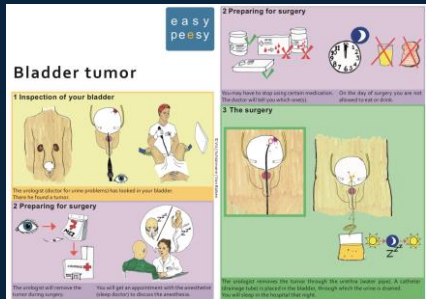
easy peesy

Bladder tumor

1 Inspection of your bladder

2 Preparing for surgery

3 The surgery



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**Video-Based Educational Tool Improves Patient
Comprehension of Common Prostate Health Terminology**

Daniel S. Wang, MD¹; Arshesh B. Jari, MD²; Muzu Sesay, MPH¹; Carolina G. Tai, MPH¹; Daniel K. Lee, BS¹; Katherine Li, PhD^{1,3}; Michael G. Goodman, MD¹; Kerry E. Kilbridge, MD^{1,3}; and Vinay A. Master, MD, PhD¹



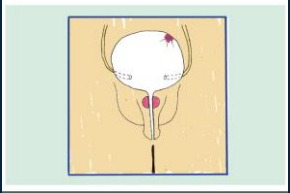
Uploads: **Prostate**



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Wang DS, et al. Video-Based Educational Tool Improves Patient Comprehension of Common Prostate Health Terminology. Cancer. 2015;121(9):733-40

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