

Start	End	Topic	Speakers
14:30	14:35	Welcome and Introductions	Joanne Robinson
14:35	14:55	Stigmatisation as a challenge to the self-concept of women experiencing urinary incontinence	Amy Hunter
14:55	15:10	Low health literacy: Prevalence and impact	Michael van Balken
15:10	15:25	Improving information transferral to patients with low health literacy	Florine Schlatmann
15:25	15:45	A specialist nurse-led clinic for men with lower urinary tract symptoms (LUTS): From referral to treatment	Anna Martinson De Cardenas Marianne Fehrling
15:45	16:00	Questions	All

Aims of Workshop

This workshop focuses on the impact of stigmatization and low health literacy on delivery of continence care. Stigmatization and low health literacy will be discussed as risk factors to the accessibility and acceptability of continence care. Best practices for outreach, communication, education, and support of patients with incontinence will be discussed. Creation of a specialty nurse-led clinic in response to unmet needs of men with lower urinary tract symptoms (LUTS) will be presented.

Learning Objectives

1. Recognize efforts by incontinent women to avoid stigmatization and its effect on engagement with healthcare professionals.
2. Discuss the prevalence and impact of low health literacy in relation to continence care delivery.
3. Describe best practices for delivery of continence care.

Target Audience

Conservative Management

Advanced/Basic

Basic

Amy Hunter, Nurse, UK

Stigmatisation as a challenge to the self-concept of women experiencing urinary incontinence

Stigmatisation is based on socially-constructed value systems. It requires that the stigmatised and the stigmatiser have shared understanding of the stigmatising condition (Goffman, 1963). Behaviour of both parties may be a reaction to the danger perceived, leading to devaluation of the stigmatised person. The way in which women with continence difficulties respond to the issue may be in part due to the threat of stigmatisation (Southall et al., 2015). Keeping symptoms secret ensures that women are able to avoid stigmatisation and maintain their identity. Two case studies, developed in the UK using Q Methodology, will be presented which highlight differences in attitudes towards urinary incontinence, how stigmatisation might be avoided and the implications for healthcare.

The first case study will present a woman who believes urinary incontinence is not normal and can be cured. Her search for a cure has predominantly been conducted via the internet. Information-gathering is prioritised to ensure that secrecy can be maintained. Due to concern of being stigmatised, disclosure is problematic. Managing incontinence alone is the best way of maintaining a continent-identity. In the past she has sought professional advice, however attitudes of professionals reinforced the idea that coping alone was her responsibility. If this woman were to access primary healthcare in future, she would prefer to talk to a nurse. Nurses are perceived to be female and have more time than doctors.

The second case study will present a woman who believes that urinary leakage does not affect her daily life. She is not embarrassed because the leakage she experiences is considered minimal and is a consequence of ageing. She does not consider her urine leakage to be incontinence. Her understanding of incontinence is related to severity and frequency. Practical adaptations have been made to daily routines to ensure continued enjoyment of activities. Pads are used and changed regularly, as odour is a concern. This woman is in receipt of professional support and is able to actively discuss issues with healthcare professionals and friends. She considers herself pro-active and supportive of peers experiencing continence issues. The nature of existing relationships, be that with healthcare professionals or friends, determines what information is shared.

An exploration of the issues raised by the cases will be discussed, focussing on some of the challenges and opportunities that are available to professionals. The “take home message” is that challenges faced by women due to stigmatisation are nuanced. Recognising the methods used by women to avoid stigmatisation can ensure appropriate and personalised care.

References

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, New Jersey: Prentice Hall.
Southall, K., Jutai, J., Van Den Heuvel, E., Fraser, S., Atomei, C., & Tannenbaum, C. (2015). Preserving and protecting self-perceptions: Responses to the stigma associated with continence difficulties in older women. *Neurourology and Urodynamics*, 34, S213-S214.

Michael van Balken, Urologist, Netherlands

Low health literacy: Prevalence and impact

What is health literacy? Is it the same as not being able to read? Why is it a problem? Questions like these will be answered initially to provide background information. Think about items as prevalence, how it differs worldwide, why it leads to extra costs and what it means for patients. Known groups at risk for low health literacy will also be reviewed and barriers to communication about incontinence will be discussed. Special attention will be paid on how to recognize patients with low health literacy as they tend not to reveal themselves. This calls for better awareness amongst healthcare providers and an active approach to deal with the problem, including the potential role for mobile/electronic applications/resources to improve continence literacy.

Florine Schlatmann, Urologist, Netherlands

Improving information transferral to patients with low health literacy

Various approaches and materials for informing and diagnosing patients will be explained. One example is the alternative “Visual Prostate Symptom Score” (VPSS) for the current International Prostate Symptom Score (IPSS). Another example is information leaflets with images instead of only text, which was recently implemented by the Dutch Association of Urology. The read-aloud function on websites and spoken animations will also be discussed. Let’s make things better!

Anna Martinson De Cardenas, Nurse and Urotherapist, Sweden

Marianne Fehrling, Urotherapist, Sweden

A specialist nurse-led clinic for men with lower urinary tract symptoms (LUTS): From referral to treatment

The number of men seeking help due to lower urinary tract symptoms (LUTS) is firmly increasing due to the increased number of aging men. Another reason is the increased concern for prostate cancer. In Sweden, we have something called the standard care course, which prioritizes programs against prostate cancer, bladder cancer and kidney cancer. Patients with suspicious symptoms related to these pathologies are offered a doctor consultancy within two weeks. The down side of this is that all other patients with benign urologic diagnoses sometimes have to wait up to 2 years for the first appointment. This unfortunately also includes patients affected by urinary retention and even urosepsis. In order to improve access to care for these patients, in 2016 we started a specialist nurse-led clinic in the urology outpatient department, where we attend men with LUTS. We are two urotherapists responsible for this. Once a week we attend 5 patients for one hour each for documentation of their medical history, transrectal ultrasound and discussion of possible treatments and solutions. The aim of our presentation is to share our work from referral to treatment, by telling you about: how we select the patients; the documents we use; the anamnesis we take; the examination we do; and the criteria we follow when choosing and offering different treatments or solutions to the patients. Periodically, when the patients have gone through all the examinations, we discuss our findings with the urologist responsible for these patients. The creation of this nurse-led clinic has decreased the waiting time from referral to first appointment, from previously up to 2 years to currently a couple of months. Our “take-home message” is that opening a specialist nurse-led clinic for men with LUTS, with consultant back-up, has resulted in reduced waiting time to see a professional and at the same time less worries for the patient.

References

Regional medical guideline: Distribution of responsibilities between general medicine and urology department in the management of LUTS. Set by the health director of the Council of Västra Götaland. Valid until April 2019.