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<tr>
<td>08:00</td>
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<td>1. An international comparative analysis of recommendations</td>
<td>Adrian Wagg</td>
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<td>for the management of incontinence with containment products</td>
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<td>08:20</td>
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<td>2. Prescribing containment products with respect to optimal use in</td>
<td>Marco Blanker</td>
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<td>3. Standardized assessment; Which questions to ask for a toileting</td>
<td>Paul van Houten</td>
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<td>and containment strategy?</td>
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<td>09:00</td>
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<td>4. Development of quality outcome indicators to improve the quality</td>
<td>Joan Ostaszkiewicz</td>
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<td>of urine and fecal continence care</td>
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<td>09:20</td>
<td>09:30</td>
<td>Discussion</td>
<td>Paul van Houten, Marco Blanker, Adrian Wagg, Joan Ostaszkiewicz</td>
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**Aims of Workshop**

- To show that not a lot of guidance is given for the daily management of continence care with containment products in clinical guidelines
- To explain a model/approach developed in the Netherlands to have GP’s/continence nurse prescribe or recommend containment product types that make the best possible match between needs/preferences and supplied product
- Which questions to ask for a toileting and containment strategy.
- Incontinence among other problems in frail elderly. The role of the holistic care plan in multi problem cases: loneliness, pain, nutrition, oral health, exercise, continence care.
- Which outcomes (KPI’s) are we looking for in the daily management of incontinence with a toileting and containment strategy?

**Learning Objectives**

1. How to assess the needs and preferences for continence care and containment
2. How to match needs and preferences in toileting and containment
3. What are good KPI’s for containment and toileting strategies

**Target Audience**

People interested in conservative Management

**Advanced/Basic**

Basic

**Suggested Learning before Workshop Attendance**

Alzheimer Europe. Improving continence care for people with dementia living at home. [https://www.alzheimer-europe.org/Publications/Alzheimer-Europe-Reports](https://www.alzheimer-europe.org/Publications/Alzheimer-Europe-Reports)


Urinary and faecal incontinence are associated with considerable stigma and a negative impact on mental and physical health, and quality of life [1]. Many older persons view incontinence as an inevitable consequence of normal ageing and cope with the problem on their own rather than seeking health care advice [2]. Up to 77% of women manage incontinence with containment products on a daily basis despite receiving other treatments [3]. Patients managing incontinence with containment may require a wide variety of products, individually tailored to meet their needs [4], but there is a lack of expert advice and support in the selection of products [5]. Over recent years, there has been a proliferation of evidence-informed guidelines on the diagnosis, assessment and management of both UI and FI. Clinical guidelines set out detailed treatment approaches, but typically say less about the use of containment products and other devices to support social continence. In order to identify gaps in recommendations for supportive management of continence care, we sought to identify to what extent containment products are included in guidelines for the management of incontinence in a range of countries, to what extent guidelines specify their use and to identify areas for future exploration.

We used a two stage approach; data on product use, and references to their use in national and international guidelines were sought and synthesised. This was followed by qualitative interviews from which data were used to confirm and enrich the obtained information from the initial phase. International, national and regional guidelines for the care of UI and FI in community dwelling adults covering Canada, Germany, The Netherlands, Poland, Spain, Sweden, and UK were examined. A structured search of guideline hosting databases was undertaken in addition to local searches in the selected countries for guidelines with relevant focus. All were compared to a reference standard, ISO 15621 [7] to provide a systematic analytical framework. A series of interviews was held with expert clinicians to identify any further guidelines and to gain insight into the use of guidelines with respect to product use. Experts were recruited by the snowball technique. Although the study concentrated on national guidelines, regional and local guidelines were included if they were reported to have a significant influence on practice.

Forty-four guidelines referring to the use of containment products for incontinence were identified in the seven countries. The need for a standardised clinical approach was the main driver for guideline development. Improvement of patient quality of life was an important driver for guideline development in Poland and The Netherlands. Most countries recommended a detailed assessment process, individualised to the patient. Compared to the reference standard ISO 15621 [6] factors such as individual preferences, priorities and circumstances, and a wide assortment of absorbent products from which to choose were variably covered in national guidelines. Despite containment being a core component of care for many patients with either urinary or faecal incontinence, there remained an unmet need for evidence-informed guidance as to the use and individualization of, and assessment of outcomes with, containment products. Individualised assessment of patient and caregiver needs for containment products, especially in those with co-morbidities, along with the provision of emotional support to patients and caregivers, and face-to-face active questioning by healthcare professionals is consistent with the framework of person-centred nursing. A number of factors which could be included in guidelines to address gaps in the assessment for, and selection of, an appropriate containment product exist and will be presented and discussed.


2 Marco Blanker, General practitioner Netherlands
Prescribing containment products with respect to optimal use in daily circumstances

In the Netherlands pharmacist, medical specialty stores and nation-wide operating companies deliver containment products to patients with incontinence. Materials are fully reimbursed in case incontinence lasts for more than two months and patients experience considerable burden. Patients annually pay the first 385 Euro’s of the costs. A prescription from a general practitioner (GP) or specialist is needed for the reimbursement. Health insurance companies determine who may deliver the products.
A recent survey showed quite shocking results with GPs admitting that they hardly provide additional care when a patient requests for a prescription of containment products for urinary incontinence. Although this doesn’t mean that GPs don’t provide adequate incontinence care in others, for those requesting a prescription, this care is at least suboptimal. To improve incontinence care, patient advocates have initiated a working group that included governmental representatives, health insurance companies, pharmacists and deliverers of containment products. This has led to the incontinence care module. In this module, a detailed description is given what continence care should be like. Three patient groups are defined; those who use containment products at own initiative, and patients from primary care, or secondary care. Caregivers should be involved in the identification of incontinence, formulating a care request, and especially in formulating a care plan. This care plan should include adequate care, aimed at lessening the burden of incontinence by ways of providing curative treatment. For the period until treatment is effective, and in patients for whom no active treatment is available, containment products should be provided.

Continence nurses, and pharmacist assistants, are involved in the search for the most adequate product to be used. For this, the PES-plus-structure is applied. PES refers to Problem, Aetiology, Symptoms. Plus refers to the daily functioning of the patient. Patients, who are wheelchair-bound or otherwise inactive, have other needs than patients who are mobile and very active. Intended functioning, objectives and human related intended use (HRIU) are than defined and matching materials are chosen. In this way, containment products should be optimised for daily circumstances. From 2019 onwards, this module should be followed. It appeared, however, that many pharmacists are not known with this. The shift towards the delivery of containers products by nation wide operating companies may also impair the implementation of this module, as personal and trusting contact seems a necessity for this.

3 Paul van Houten, Specialist elderly care, Netherlands
Standardized assessment; Which questions to ask for a toileting and containment strategy?

In the Netherlands there is a growing awareness that quality instruments that are only based on evidence, quality indicators and fill in lists are doing to little for the perceived quality of care. When there is evidence for a specific program concerning a single care problem (for instance prompted voiding for demented people with urinary incontinence) this program is implemented but it is very difficult to maintain in the long run. There are several reasons for this: other programs for other care problems are being introduced also, staffing problems, too much paper work. Most programs end up with a lot of paper work for the care staff and the reason why the program was started is not as clear anymore. Because the care needs are very different and the care process is complex, now the emphasis is back to what the client and his/her family finds important. This awareness leads to a program that sets the needs of the client central. A new quality framework was developed alongside a budget increase aimed to have more nursing staff. This program has the following assumptions: A client is a person with caring needs and his own history, future, goals, context and loved ones. The care plan must reflects this. The focus of the personnel must be on learning and trust. The quality of the learning process is very important for transparency and supervision of government and payers. In this context, continence care is one of the issues that can be important for a client, but must be regarded in the context of personal goals and other issues. So there is not a bold continence framework anymore with a program that must be available for all clients but individual toileting and containment goals. In setting these goals, the needs and preferences of the client are important but also the craftsmanship of the caring staff. This gives the need for an individualized toileting and containment decision tool that can be used in all kind of care settings, in an institution but also at home. This tool must enhance the knowledge of nurses and nursing aids. Therefor a multidisciplinary international expert panel was convened to identify the input for a decision support tool. This tool will assist health care professionals who are not specialized in incontinence care to assess individuals with urinary and/or fecal incontinence and recommend appropriate person-centred management options. Because incontinence is strong related to toileting abilities it is important to take in account options to improve those abilities or to give proper aid. When there is a goal in the field of long lasting incontinence and there is a focus on self-management, than this implies that certain products types work better for certain groups of people, e.g. example of pants type in people with mild to moderate dementia. In the workshop is explained how this tool is constructed.

4 Joan Ostaszkiewicz, Nurse, Australia
Development of quality outcome indicators to improve the quality of urine and fecal continence care

Toiletting and containment strategies are integral to protecting the dignity of people with incontinence. The combined use of containment products and toiletting can prevent, improve and/or manage incontinence, promote a person’s independence and autonomy, and is equally beneficial and important for people with UI and FI, all ages, across all diagnoses and conditions. Despite this, there is a marked lack of auditable quality standards for this approach. To address this gap, an international expert panel was established to conduct a scoping review, stakeholder engagement, and expert consensus. The consultative process resulted in 14 key performance indicators (KPIs) that offer guidance with respect to toiletting and containment strategies for people who are independent as well as dependent. This presentation describes the KPIs and presents a set of factors that healthcare practitioners need to consider when recommending a toiletting and containment strategy. Not every medical intervention will work for incontinence. Supporting people to live with incontinence involves shifting the incontinence paradigm.
from cure to care and helping people cognitively and psychologically adjust. Toileting and containment strategies are central to living well with incontinence.

References


Workshop

Shifting the Incontinence paradigm from cure to care: What to offer when medical interventions fail

All about: Patient centred continence care!

Affiliations to disclose:

No financial ties

Unpaid counsellor for essity

Funding for speaker to attend:

☐ Self-funded

☐ Institution (non-industry) funded

☐ Sponsored by:

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Step 1, open app and select programme by day

Step 2, locate workshop

Step 3, scroll to find evaluation button

Step 4, complete survey
Recommendations for the management of incontinence with containment products: what do the guidelines say?

Affiliations to disclose:
Consultancy, research grants and speaker honoraria from Essity Health & Hygiene, AB.

Funding for speaker to attend:
- Self-funded
- Institution (non-industry) funded
- Sponsored by:

Introduction
Despite the many treatments available up to 77% of women manage incontinence with containment products on a daily basis.
Inappropriate use of containment products is common, seen in up to 50% of in hospital patients.
People managing incontinence with containment may require a wide variety of products, individually tailored to meet their needs, but there is a lack of expert advice and support in the selection.

In a survey of Canadian women...

- European Association for Urology guidelines for UI consider containment devices last resort in women, frail older persons and people with limited or no mobility.
- ISO 15621:2017 notes factors to consider when choosing absorbent incontinence aids:
  - the particular needs of the end user (e.g. the nature and severity of their incontinence);
  - the needs of an assisting caregiver (e.g. ergonomics in the design of the product);
  - the design of the aids and cost;
  - environmental factors.
- ISO16021:2000 considers basic evaluation of patients.

Incontinence management with containment products remains heterogeneous with wide variations in assessment, product availability and financial support.
In order to identify gaps in recommendations for supportive management of continence care, we sought to identify to what extent containment products are included in guidelines for the management of incontinence, and to what extent guidelines specify their use.

Explanatory mixed methods study.

In the initial, knowledge synthesis phase, data on product use, and references to their use in national and international guidelines were sought and synthesised.

This phase was followed by qualitative interviews. Data from the qualitative phase were used to confirm and enrich the data from the initial phase.

International, national and regional guidelines for the care of UI and FI in community dwelling adults covering Canada, Germany, The Netherlands, Poland, Spain, Sweden, and UK were examined.

A structured search of guideline hosting databases:
- Cochrane
- National Health Service UK (NHS) evidence
- Database of Abstracts of Grey Literature (DAGL)
- Health Technology Assessment (HTA)
- NHS Economic Evaluation Database (NHS EED)
- National Institute for Health Research (NIHR) monographs
- Guidelines International Network (GIN),
- National Guideline Clearing house (NGC)
- Turning Research Into Practice (TRIP)

A series of interviews was held with expert clinicians in each country to identify guidelines not revealed by the electronic database searches and to gain insight into the use of guidelines with respect to product use.

Experts were recruited by the snowball technique following initial introductions by members of the study steering group.

Regional and local guidelines were included if they were reported to have a significant influence on practice.

Forty-four guidelines referring to the use of containment products for incontinence were identified in seven countries. The need for a standardised clinical approach was the main driver for guideline development in Poland and The Netherlands, improvement of patient quality of life was also an important driver.

Education and support

- Provision of emotional support for patients was mentioned only in UK guidelines.
- The majority of countries recommended some form of caregiver education.
- The majority of countries recommended the consideration of patient preferences in the treatment of incontinence.
- Consideration of caregiver preferences was only identified in German guidelines.
- Consideration of patient autonomy in the selection of containment product was mentioned in guidelines from Germany, The Netherlands and Spain.
Other related factors

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<th>Skin health</th>
<th>Comfort and ergonomics</th>
<th>Discretion needs of carers</th>
<th>Disposal and laundry facilities</th>
<th>Sustainability and environmental impact</th>
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Outcome measurement

The most commonly mentioned measure of success for any treatment was patient reported improvement. A variety of measures was suggested:

- incontinence diaries
- global response scales
- achievement of personal goals
- patient experience surveys
- patient complaints
- pads prescribed per month (Spain)
- resource cost per month (Spain)
- physician reported improvement (Poland)

There was little other mention of how commonly, or in what circumstances, these measures were recommended for use.

Interviews

Of 21 local experts; the majority (57%) felt there was a need for specific standardised guidance on choice and ongoing use of containment products. Other opinions:

- a lack of current overall guidance for incontinence (Canada, Germany)
- guidance was based too heavily on urinary incontinence (Spain)
- not practical for everyday clinical use (Spain, UK).

Experts also noted the variability in access to, or eligibility for, financial support for containment products

There was also a felt need for educational initiatives for healthcare professionals as part of guideline implementation (Poland, Spain).

Summary

**BASIC REQUIREMENT**

- Individualised assessment of patient and caregiver needs
- Provision of emotional support to patients and caregivers
- Face-to-face active questioning by healthcare professionals

**REQUIRES INCLUSION / CONSIDERATION**

- Patient discretion
- Disposal and laundry facilities
- Environmental impact
- Product safety
- Total cost

Management

**REQUIRED**

- evidence-based algorithms targeted to individual patient profiles to provide specific guidance for care providers
- education in all aspects of their/their patients’ incontinence care to ensure appropriate management for containment.
- full involvement and inclusion of patients and caregivers in containment for incontinence

Patient preference was the main driver for selection of containment product, practical considerations and severity of incontinence considered only to a lesser extent.

Containment products should be selected considering:

- patient preference
- practical limitations (for example: environment, anatomy, gender, patient autonomy/mobility)
- social factors
- severity of incontinence.

Use of resources such as the independently resourced continence product advisor (http://www.continenceproductadvisor.org/) should be promoted, and similar resources in languages other than English (for example the Swedish Nikola website (http://nikola.nu) should be encouraged.
Maximizing uptake and monitoring performance

Need for specific education on the guideline content for practitioners and inclusion of incontinence assessment and management in overall measures of health.

Assessment of the performance of containment products in terms other than those of product related factors should be included.

Also needed:

- guidance on how to support effective team-working between professionals managing the patient
- assurance of appropriate professional competencies in continence assessment and initial management.
- consideration of containment as a primary management option if this is the patient’s preference, or should other treatments fail.
W3: Development of quality outcome indicators to improve the quality of urine and fecal continence care

Dr Joan Ostaszkiewicz
Centre for Quality & Patient Safety Research
Deakin University
Australia

Joan Ostaszkiewicz

Affiliations to disclose†:
Essity – travel fees 2018 /consultant fees 2019
Unicharm – consultant fees 2017

Funding for speaker to attend:
☐ Self-funded
☐ Institution (non-industry) funded
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While being trained as a physician and scientist had helped me process the data and accept the limits of what that data could reveal about my prognosis, it didn’t help me as a patient. Like my own patients I had to face my mortality and try to understand what made my life worth living (Kalanithi, 2016. p. 139).

'I had learned something, something not found in Hippocrates, Maimonides or Osler: the physicians' duty is not to stave off death or return patients to their older lives, but to take into our arms a patient and family whose lives have disintegrated and work until they can stand back up and face, and make sense of, their own existence' (Kalanithi, 2016. p. 166)

The cure paradigm influences how:
• Health services are structured and delivered
• The content of education programs and how they are delivered
• Health care messages are framed and delivered
• Healthcare priorities are determined
• Research is funded
• Clinical interactions play out
• Healthcare interventions are evaluated
Cure rates for incontinence

- Surgery for stress UI: 82.3% (IQR, 72–89.5%)
- Medications for urgency UI: 49% (IQR, 35.6–58%)
- Pelvic floor muscle training: 58–83.4%
- Sacral neuromodulation for FI: 38.6% (IQR, 35.6–40.6%)

Public

Neurological disorders that increase the risk of incontinence

(Apostolidis et al., 2017)

- Dementia
- Constipation and Faecal Incontinence in dementia
- Normal pressure hydrocephalus
- Multiple system atrophy
- Parkinson's disease
- Cerebral lesions and CVAs
- Meningitis-retention syndrome
- Acute disseminated encephalomyelitis
- Spinal canal stenosis
- Cauda equina syndrome
- Transverse myelitis
- Neuropathies and muscle disorders
- Familial amyloid polyneuropathy
- Familial dysautonomia
- Charcot-Marie-Tooth disease
- Autonomic neuropathies
- Disorders of the neuromuscular junction
- Muscle disorders
- Multiple sclerosis
- Spinal cord lesions
- Spina bifida
- Diabetes mellitus

Possible negative effects of the ‘cure paradigm’ on patients

- Cognitively vacillate between hope and despair
- Causes people to internalise failure
  - I didn’t do the pelvic floor exercises as I should
  - It is my fault
  - I am overweight
  - I am too old
- Delays effective management

Reframing the goal to include care involves……

- Helping the person to:
  - Understand their own body and how it works, including how to accommodate an unpredictable bladder or bowel
  - Recognise and reject the social stigma of incontinence
  - Develop strategies to conceal and contain incontinence
  - Develop healthy toileting regimes, including awareness of toilet accessibility, location etc
- Recognising and responding to carers’ needs for advice and support about day to day management

‘A lack of dignity in the form of neglect of personal care and verbal abuse: i.e. nursing staff acting in an intimidating manner, deferring or failing to appropriately toilet older people, aggressively washing a consumers’ genital areas and failing to address their need for hygiene assistance’ (Graves et al., 2017. The Oakden Report)
Coercive, abusive continence care
- Chastising a person for incontinence
- Overriding a person’s attempts to resist continence care

Neglectful continence care
- Restricting a person’s access to toileting assistance or containment products
- Withholding or delaying responding to requests for help to maintain continence or to manage incontinence
- Breaching a person’s privacy (Ostaszkiewicz 2018)

Public

References
Standardized assessment: Which questions to ask for a toileting and containment strategy?

P van Houten, MD, PhD

Content

Types of quality programs for care

- What is the value of care for NH clients
- Situation in Dutch nursing homes
- Construction of a toileting and containment decision tool
- Take home message

Programs for single care problems

- Mostly evidence based
  - Research, Program; Lists with questions (assessment) and management directives, quality indicators
  - Distrust craftsmanship
  - List more important than patient
  - Prompted voiding
  - Labor intensive
  - Difficult to maintain

Types of programs for Quality Improvement in NH Care

- Integrated programs

  Compilation of evidence based programs
  - You can not see the patient behind the lists

- Value based programs (patient centred)

  - Patient own needs, history, goals, context.
  - Emphasis not primary on evidence
  - Measuring experienced quality
  - Learning and trust, quality of learning important
What is value for 117,000 Dutch NH clients

- All severely physical handicapped
- ¼ memory problems, 40% dementia
- 2 or more chronic conditions
- ¾ weekly visit by family member
- ¾ never outdoors

Problems with:
- pain, sleep, loneliness, activity and cognition

Prevalence of Urinary Incontinence in Dutch nursing homes

Source: LPZ 2014

Prevalence of Double Incontinence in Dutch nursing homes

Source: LPZ 2014

What happened?

- Improvement to toilets in nursing homes
- Continence care also an issue for management
- Emphasis on abilities instead disabilities (positive care)
- Emphasis on patients personal circumstances and goals
- Education of staff (awareness of difficulties for patients to reach the toilet)

Address toileting and containment together integrated in value based care (in context of pain, sleep, loneliness, activity and cognition).

Construction of a toileting and containment decision tool

Aimed for
- Not specialized in (in)continence care
- How and what to assess?
- Person-centred management options in toileting and containment
- Focus on self management and improving abilities

In the context of fading boundaries between home and institutional care

Accepted for WOON aug 2019

Expert Panel

- Paul van Houten (physician elderly Care)
- Diane Newman (nurse practitioner)
- Helle Wijk (registered nurse)
- Barbara Koehler (physiotherapist)
- Andrew Costa (health research)
- Edward Hutt (Market Access)
### Strategies

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<td>Containment product types</td>
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### Toileting strategies

- **Physical environment**
  - Toileting programs when patient needs help
    - On demand
    - Scheduled/prompted voiding

- **Bladder retraining options**

- **Toileting aids**
  - Urinal
  - Commode/bedpan
  - Toilet seat raise

- **Personal hygiene aids**
  - Wiping aids
  - Advanced water based toileting systems

### Value

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<td>Social factors</td>
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### Social factors

- Does your bladder problem occur while you are at your job, or carrying out normal daily activities outside home?
- Does your bladder problem occur when you are travelling?
- Is your bladder problem brought on by physical activities whether at work or leisure, for example going for a walk, running, sport, gym, etc.?
- Does your bladder problem affect your sex life?
- Does wearing a containment product make you feel uncomfortable or embarrassed about yourself?

### Take home message

- Base your strategies not only on single issue guidelines but on value for the patient
- Base your strategies on the combination of toileting and containment.
- Make toilets available and usable
- See that nurses and nursing aides are trained and get the tools to make care plans.
- Organize instructions for informal caregivers
Prescribing containment products with respect to optimal use in daily circumstances

Marco H. Blanker, MD PhD
General practitioner and epidemiologist
lead of research group pelvic- and abdominal symptoms
Department of general practice and elderly care medicine, University of Groningen, The Netherlands

Content

Containment product delivery in the Netherlands

- Where are we?
- Where are we heading?

Where are we?

Dutch GP guideline UI in females (2015):

- Discuss the option of using containment products with the woman. Refer women who want to, depending on the health insurer, to the pharmacy or an (online) supplier of medical devices.
- The woman can receive guidance in the pharmacy or from a (district) nurse trained therein in choosing and using a certain product.
- It is recommended to evaluate the use of women who use containment products periodically (for example, once a year) (points of interest: satisfaction with childcare material, whether or not they want treatment).

Where are we?

Dutch urologist / gynecologist guideline UI in females (2011):

- Detailed advice on type of containment product and which aspects to consider

Where are we?

Retrospective cohort study in primary care

402 women with UI from 196 different GPs

14% of women received prescription for containment product
63% of these women received no other treatment

Evaluation of effect: never

Find problem in the shift from cure to care in incontinence is that cure is (very) disappointing.
Where are we?

Prescription = reimbursement

2017: 443,100 patients (with prescribed products)
137,302,000 Euro’s

Delivery through local pharmacy or nation wide operating medical specialty companies

Day price method: severity of UI leads to maximum reimbursement

Profile 0 = 12 EuroCENT / day  Profile 7 = 3.30 Euro / day

Where are we heading?

General opinion / feeling that continence care is inaccurate

✓ 4 patient organizations
✓ continence nurses
✓ health insurance companies
✓ pharmacists / medical specialty stores
✓ health ministry

Notably: no physician organizations took part

Module continence aids

Identify the problem

patient

(important role for caregivers – especially GPs and GP assistants)

Formulate request for care

nurse / PA: apply PES-structure:

Problem
Etiology
Symptoms

Add “functional diagnosis”
Module continence aids

Make a care plan
GP / physician assistant OR nurse / PA

Define intended functioning
Targets: “human related intended use” (HRIU)

Module continence aids

Make a care plan
Nurse / PA

Define intended functioning
Targets: “human related intended use” (HRIU)
Product related intended use (PRIU)

Define size, material and version of containment product
= personalised choice
=> pharmacy or medical specialty score

Module continence aids

4. Select, test, decide
5. deliver and provide instruction
6. use
7. evaluate

Where are we heading?

So, in theory, patient is in the lead
Prescription of containment products is adapted to patient needs
Since January 1st, 2019, mandatory for all containment providers

BUT
Many pharmacies are unaware of this method
Physicians not involved and seemingly not interested
Impact of this method on quality of care is unknown (currently under study)

Insurance companies refuse to withdraw day-price method
Important shift towards nation wide companies without any face-to-face contact/care

In summary

Dutch primary care for incontinence is low-quality
Many women don’t receive proper care
- containment products are not prescribed
- containment products are prescribed without any other option

For the delivery of containment products
- we are looking in the right direction, with patient centered care
- are we moving in the right direction?
  - need to identify barriers & facilitators
  - study impact of his patient centered care

Prescribing containment products with respect to optimal use in daily circumstances

Thank you for your attention!

@Marco_Blanker
m.h.blanker@umcg.nl
While being trained as a physician and scientist had helped me process the data and accept the limits of what that data could reveal about my prognosis, it didn’t help me as a patient. Like my own patients I had to face my mortality and try to understand what made my life worth living (Kalanithi, 2016. p. 139).

'I had learned something, something not found in Hippocrates, Maimonides or Osler: the physicians’ duty is not to stave off death or return patients to their older lives, but to take into our arms a patient and family whose lives have disintegrated and work until they can stand back up and face, and make sense of, their own existence' (Kalanithi, 2016. p. 166).

The cure paradigm influences how:

- Health services are structured and delivered
- The content of education programs and how they are delivered
- Health care messages are framed and delivered
- Healthcare priorities are determined
- Research is funded
- Clinical interactions play out
- Healthcare interventions are evaluated
Cure rates for incontinence

- Surgery for stress UI: 82.3% (IQR, 72–89.5%)
- Medications for urgency UI: 49%; IQR, 35.6–58%
- Pelvic floor muscle training: 5–83.4%
- Sacral neuromodulation for FI 38.6% (IQR, 35.6–40.6%)

Possible negative effects of the ‘cure paradigm’ on patients

- Cognitively vacillate between hope and despair
- Causes people to internalise failure
  - I didn’t do the pelvic floor exercises as I should
  - It is my fault
  - I am overweight
  - I am too old

Neurological disorders that increase the risk of incontinence

(Apostolidis et al., 2017)

- Dementia
- Constipation and Faecal Incontinence in dementia
- Normal pressure hydrocephalus
- Multiple system atrophy
- Parkinson’s disease
- Cerebral lesions and CVAs
- Meningitis-retention syndrome
- Acute disseminated encephalomyelitis
- Spinal canal stenosis
- Cauda equina syndrome
- Transverse myelitis
- Neuropathies and muscle disorders
- Familial amyloid polyneuropathy
- Familial dysautonomia
- Charcot-Marie-Tooth disease
- Autonomic neuropathies
- Disorders of the neuromuscular junction
- Muscle disorders
- Multiple sclerosis
- Spinal cord lesions
- Spina bifida
- Diabetes mellitus

Reframing the goal to include care involves ......

- Helping the person to:
  - Understand their own body and how it works, including how to accommodate an unpredictable bladder or bowel
  - Recognise and reject the social stigma of incontinence
  - Develop strategies to conceal and contain incontinence
  - Develop healthy toileting regimes, including awareness of toilet accessibility, location etc
- Recognising and responding to carers’ needs for advice and support about day to day management

‘A lack of dignity in the form of neglect of personal care and verbal abuse: i.e. nursing staff acting in an intimidating manner, deferring or failing to appropriately toilet older people, aggressively washing a consumers’ genital areas and failing to address their need for hygiene assistance’ (Graves et al., 2017. The Oakden Report)
No toileting assistance

- USA (22.8%)
- Italy (12.3%)
- Denmark (6.6%)
- France (5.3%)
- Japan (4.3%)
- Sweden (2.7%)
- Iceland (2.7%) (Sgadari et al., 1997)

Toiletted according to
- Staff convenience
- Routine/ritual

Coercive, abusive continence care
- Chastising a person for incontinence
- Overriding a person's attempts to resist continence care

Neglectful continence care
- Restricting a person's access to toileting assistance or containment products
- Withholding or delaying responding to requests for help to maintain continence or to manage incontinence
- Breaching a person's privacy (Ostaszkiewicz 2018)

References