

W16: Patients' potentials for good continence care in local communities

Workshop Chair: Laszlo Szabo, Hungary
03 September 2019 14:00 - 15:30

Start	End	Topic	Speakers
14:00	14:15	Introduction and overview Existing situation in incontinence care in Hungary	Laszlo Szabo
14:15	14:30	Barriers and suggested KPIs. Existing situation in incontinence care in SLO	Bozidar Voljc
14:30	14:45	Patients' potentials on individual, family and society level	Eszter Vidor
14:45	15:00	Existing situation in incontinence care in CRO. Suggestions for a local approach by existing community potentials.	Ivica Belina
15:00	15:30	Discussion	Laszlo Szabo Bozidar Voljc Eszter Vidor Ivica Belina

Aims of Workshop

To present and discuss existing practiced, mal-practiced and not practiced rights in incontinence care from patients perspective, to identify regional problems and suggest solutions for common challenges. The focus will be on assessing patient needs, the process of continence care delivery and the importance of outcome measurement and evaluation. A new model will be presented on the use of national key performance indicators for continence care delivery and ensuring efficient allocation of resources and services.

Participants will have a chance to learn the advantages and shortcomings of continence care from individual, family and community perspective.

Learning Objectives

To present current situation of continence care delivery in Hungary, Croatia, Friuli-Venezia-Giulia and Slovenia.

Target Audience

Urology, Urogynaecology, Conservative Management

Advanced/Basic

Intermediate

Hungary's first incontinence programme is the Drop of Confidence Programme

Szabó L

Our main objective is the significant and sustainable improvement in the quality of life of people living with incontinence and their caregiver relatives in Hungary, and in the neighbouring countries.

Ideal incontinence care should be: provides immediate symptomatic treatment and additional diagnostic options and causative therapy as needed. Filter out more serious illnesses that accompany incontinence or are in the background of incontinence it offers exactly the right care for your symptoms abilities and needs care is provided at as low level of progressivity as possible, thus ensuring cost-effectiveness and the principle of home care for cost-effectiveness enhances the effectiveness of applied treatments with preventive activities lifestyle counselling, and behavioural methods to improve continence puts communication tools on the destigmatization of patients and the taboo nature of the subject.

Principles. We strive for long-term care prevention. We need to set up feasible and sustainable screening systems. We recommend incontinence as a syndrome approach, taking advantage of the role of incontinence in Sentinel in certain well-defined public health areas (psychiatry / dementia, schizophrenia, ovarian cancer, prostate cancer / oncology, COPD / smoking cessation, obesity). We need to create specific, measurable, supported, integrated programs for the public health system. Hungarian incontinence guideline was published in 2016. Title is Guideline for non-neurogenic incontinence in adulthood. Renewing the guideline is under process in 2019.

Next steps linked with the guideline. Maintain a good incontinence care on primary care level GP's office, pharmacists, family care nurse. Systematic monitoring at the risk groups (family care nurse). How the GP should prescribe medicines and medical devices? GP's competence list.

Structure of the drop of self-confidence programme.

The main goal is to relieve stigma from people with incontinence and their relatives. Influencing attitudes and legal regulators of basic care. Take off some weight from urologists. Ensuring real-time close-to-home care. Ensuring the principle of equal treatment. „Long term prevention” focused care. Build up proper patient's&caregiver health literacy.

Health literacy. Our patient information program building on the principles of modern health and well-being has entered its 9th year. A series of patient support materials have been created, and the informative website of the program is www.cseppnyionbivalom.hu #PelenkApp educational mobile app was created.

Epidemiological-grade data recordings. 7 times data recorded in nearly 4600 GP practices with a total of 169,900 patients (2011-2019). 1 time data recorded in urological practices, 164 micro-regions, close to 21480 people (2018). By 2019, a Hungarian register database was created in a unique way on this basis, we have been able to create different patient profiles and setting up an authentic map of problems.

What we learned from the data? 34% percent of the Hungarian patients did not receive proper medical devices to handle stigma. Based on the cumulative data, 31% of respondents said they did not receive adequate professional help, even if they contact their GP in time 58% percent of the patients lost between primary care and urologists office without any support...

Long term prevention of incontinence - Slovenian experience

Bozidar Voljc

A long term preventive approach to incontinence – a syndrome with different forms and aetiology – needs from the clinical point of view, to consider next to the gender and age of affected persons also their functional, anatomical, behavioural, genetic and social reasons respectively circumstances. In most cases it is individually oriented and includes pelvic floor muscles exercises in pregnancy and prostate enlargement, toilet training in children, medication control, healing of urinary infections, weight reduction etc. More serious clinical causes of incontinence have to be treated according to the professional rules of gynaecology, urology, paediatrics, neurology and geriatrics. Clinical activities, regardless their reason and nature (including s.c. incontinence clinics for out-patients), have always be accompanied by secondary or tertiary prevention means, which are normally individually oriented as well. It is typical for clinical incontinence performances, that stigma, a heavy social burden of incontinence, does not play an important impediment in its treatment.

A strategic long term prevention of incontinence is a typical issue of primary prevention with a societal orientation. It is targeting communities with all their social features, which can be different in some point from other to another. They should include all ages and be supported by local stakeholders, primary health care and non-governmental organizations from the Red Cross and Caritas to different organizations of patients, e.g. hypertension, diabetes, Parkinson, Alzheimer and others in case that they are existing. Associations of people with incontinence, which members are ready to talk about their burden and experiences in public, are very rare, and should be supported by more moral and financial means, as for instance Inkont organization in Maribor.

After years of work with urban and rural communities it is an experience of the Emonicum Institute, as well as with the DryDay project, that a separate seminars or lectures of incontinence do not enjoy such popularity as for instance seminars of healthy lifestyle, health literacy, geriatric syndromes etc. That's why we started and intend to continue to combine challenges of incontinence in collaboration with local experts, with other geriatric syndromes – falls, osteoporosis, diabetes 2, Parkinson, early signs of dementia, mobility issues, ways to prolong independent life at home etc., as one of normal and most prevalent health and social problem in each community. We prepared and published also guidelines for elderly individuals with continence troubles and this year the 3rd international conference on 21. June in Ljubljana has been titled "Living with incontinence". It is our intention to empower residents in their communities with a health literacy which should reduce stigma, which still hampers politics and professions to talk about continence and their different disorders in public more directly on a national level. That's why a long term strategy for healthy and active life with incontinence and its reduction should be prepared in each country.

TREAT WELL A COMORBID SYNDROME!

Vidor Eszter Hungarian Patients Forum, DG SANTE advisor

Right to Equal Access

Rights of equal access to the same care quality if disabilities are mitigated especially the lower educated or lower income women, since even in the scope of the five major comorbid disease (cardiovascular diseases, respiratory diseases, neurological diseases, psychiatric comorbid disorders and obesity) in the European Union is not sufficiently addressed.

Tabooed stigmatizing social killer syndromes cannot be fixed at Member State level, because of complexity and limited resources. Hardly exposable social disability avalanching syndromes like incontinence and rare diseases have long term care implications can be solved out only on EU level with joint effort on the basis of medical, social, cultural and behavioural evidences we already know. The critical success factor is finding a systematic and structured solution to the key stigmatizing and comorbid syndromes prevailing in the EU is the primary care access to appropriate professional standards. Gives a space for caregiver relatives to provide good practice care, ensuring their rights and obligations in the same ethical balance! Caregivers are the next generation of cared ones for the future

Principle of Equal Treatment

Incontinence is a serious stigmatizing syndrome. Especially in that cases when the patients communication ability is limited or non-existing (children, mental disabilities, multiple disabilities, rare diseases etc.) Patient's and caregiver relative's rights is very vulnerable in this case, especially at several ethnical or undertrained groups.

65% of women and 30% of men sitting in a GP waiting room report some type of urinary incontinence, so the main problem is the lack of primary care standards. In most cases the principle of equal treatment is violated. Caregiver relatives in several cases substitute state care, quality assurance can only be achieved by linking the social cash benefits to a knowledge survey. Long term prevention is lost, when we speak about elderly or childhood nursing homes. Around 77% of nursing home residents are affected by incontinence (Steel & Fonda 1995: Minimising the cost of urinary incontinence in nursing homes, Pharmacoeconomics). 40-60% of people in nursing homes will wet the bed tonight (Steel & Fonda 1995: Minimising the cost of urinary incontinence in nursing homes, Pharmacoeconomics).

Roadmap

- Focus on key tabooed disabilities having extreme high negative social impact (incontinence)
- Inclusion of all age group (childhood, adulthood, elderly)
- Address prevention profiles (risk behaviour & / or risk group tailored methods)
- Push systematic sentinel management (early recognition of OCC, SM, PCC, etc.)
- Ultimate symptomatic treatment in primary care (drug, biofeedback, medical device)
- Considering complications & comorbidity (drug interaction, DM, etc.)
- Complex conservative care (patient profile based care)
- Persistent infection prevention Best compose of information & education (doctors, nurses, relatives, patients)
- Rights & rules (care giver license to care, KPIs, patient rights, payment, etc.)