Better care, better health - towards a framework for better continence solutions

A Summary of Stakeholder Perspectives on the Optimum Continence Service Specification

Introduction

The 5th Global Forum on Incontinence (GFI), “Better care, better health - towards a framework for better continence solutions”, was held in Madrid on 8-9 April 2014. Over 300 participants representing policy makers, payers, medical experts, patient organisations, civil society groups, health professional and carer organisations from more than 30 countries came together to learn more about the impact of incontinence on patients, carers and society and to discuss solutions to improve the quality and delivery of continence care services.

This document aims to capture the discussions and the perspectives of national and international stakeholders present at the GFI on the Optimum Continence Service Specification and its recommendations. The GFI participants were split, country by country, into three thematic groups reflecting on core themes and recommendations of the Optimum Continence Service Specification: nurse empowerment and education, integrated care and self-management. Guided by Theme Coordinators, each group discussed current barriers to better continence care and the applicability and implementation of the study’s recommendations in their country. This document presents a brief overview of the Optimum Continence Service Specification and summarises the stakeholder discussions in the GFI thematic groups regarding current barriers and available solutions for better continence care.

The Optimum Continence Service Specification

A key cornerstone of the GFI was the launch of the Optimum Continence Service Specification, a new study presenting an ideal care pathway designed to improve the quality of life and care services for community-dwelling adults living with incontinence. The Optimum Continence Service Specification is the result of one and a half years of work by a multidisciplinary panel of international experts in the field of incontinence. It was developed on the basis of careful review of existing scientific research, clinical guidelines and interviews with key opinion leaders, patient groups and healthcare providers in different regions across the globe. The study, the first in its kind in the field of incontinence, aims to provide concrete guidance to policy makers, health managers and payers for moving towards better and more efficient continence care.

The Optimum Continence Service Specification defines the care pathway for incontinence as an integrated care model. The four key components of the continence care pathway identified in this study are: case detection; initial assessment and treatment; case coordination; and specialist treatment (see picture on the left). The study’s recommendations aim to especially improve the detection and initial assessment and treatment phase of the care pathway, as preliminary research suggests this is a major area for improvement in a number of countries across the world. A comprehensive summary of the Optimum Continence Service Specification is available on the GFI Forum website. At the time of writing, this summary is waiting for publication in a peer-review journal.
Key recommendations for an ideal organisation of care for people with incontinence

Key Optimum Continence Service Specification recommendations include:

1. Ensure ease of access by the establishment of robust referral pathways from detection of incontinence through to appropriate assessment and treatment;
2. Shift the responsibility of basic continence care away from primary care physicians to continence nurse specialists in primary care, where available;
3. Where possible, use a case co-ordinator to ensure collaborative working, especially to help delay or prevent admission of patients to permanent care settings; given the general trend to more integrated clinical pathways, in particular concerning patients with multiple morbidities, it is necessary to strike a balance between specialisation and holistic case management approaches;
4. Promote use of self-management tools and techniques: provision of information on the use of containment products; use of enabling technologies; an emphasis on shared decision-making between healthcare provider and patient/caregiver; and educational campaigns on the nature of the illness and treatment strategies;
5. Specialists should be well integrated with other parts of the care pathway. They play a key role in quality governance, training and the dissemination of best practice;
6. Use a comprehensive assessment of user, product, and usage-related factors to assess the needs of patients and caregivers with regards to containment products. This process should be standardised, valid and easily reproducible. The final decision regarding choice of product should remain with the end-user: the patient and/or the caregiver;
7. The use of technology should be integral to the delivery of continence care. Technology should enable self-care and connect patients, caregivers and enable providers to monitor progress and troubleshoot problems;
8. For payers: in order to provide the highest quality continence care, ensure care standards are incentivised. This can be achieved through stipulating the achievement of targets on clinical outcomes rather than operational measures alone, careful use of quality-related financial incentives, and an emphasis on clinical governance;
9. Establish accredited programmes of training for 1) nurses wanting to become continence nurse specialists, and 2) other health or social care professionals such as social workers wishing to improve their competence in delivering continence care.

Barriers to better continence care identified by GFI participants

Low public awareness and education: national and international stakeholders identified a number of key barriers and obstacles to continence care in their home countries. Stakeholders widely agreed that stigma, low public awareness and a lack of continence-specific knowledge and training in both healthcare professionals and carers represent significant challenges to improving the standard of care for people with incontinence. Stakeholders cited feelings of embarrassment, a feeling that ‘nothing can be done’ or a belief that incontinence is normal after a certain age as key barriers in seeking expert advice. It was recognised that the level of available information about existing services and treatment options on incontinence is low both among the general public and primary care professionals. Stakeholders therefore welcomed the recommendations in the Optimum Continence Service Specification for promoting understanding of the nature of the disease and the available treatment strategies.

Incontinence is not referred to as a ‘disease’ but as a symptom, therefore there is no database of people suffering from it
GFI participant, Estonia

The main problem is this is not a ‘must do’ issue
GFI participant, United Kingdom
Insufficient case detection: stakeholders from many countries agreed that there is a need for better detection followed by appropriate assessment and treatment. Low case detection levels, it was noted, can be accounted for by a combination of persistence of misperceptions/stigma, scarce training of healthcare professionals and lack of appropriate structures (or information about existing ones) for patients to revert to. Also the lack of nurses (or similar professionals) specifically trained on incontinence was perceived as a key obstacle to efficient assessment.

Lack of integration of services: stakeholders generally felt that there is an over-emphasis on specialised care, which in turn leads to duplication of services (lack of integration between primary and specialist care). This was also found in the literature reviews referred in the Optimum Continence Service Specification. Silo thinking and a lack of integration between health and social care services was perceived as a challenge of growing dimension, especially in today’s context of ageing societies and rising demands for long term care.

Incontinence not a priority on the policy agenda: almost all stakeholders believed that, contrary to the situation today, incontinence should be a priority on the agenda of policy makers, health administrators and decision-makers across health and social care.

Lack of continence-specific training for healthcare professionals: stakeholders viewed the general lack of incontinence-specific training and education of all health professionals involved in the first phases of the care pathway (i.e. detection and initial assessment and treatment) as a critical obstacle in delivering better continence care. General Practitioners (GPs), they noted, are currently regarded by most patients, carers and professionals as the first point of contact in the case detection and initial assessment/treatment phase. However, given GPs’ heavy workload and generalist background, stakeholders acknowledged that it would be sensible to shift the first assessment to specially trained health and social care professionals with more background knowledge on incontinence. Nurses might also be more easily educated in continence care than other professionals and, once specialised, be empowered to perform tasks such as preliminary physical examination and prescription of basic treatment/containment products.
Incontinence should be an important part of the education of nurses and of carers
GFI participant, Sweden

For such a shift of roles in the initial assessment and treatment phase to happen, it is essential that: 1) basic continence-specific education curricula are developed for all healthcare professionals involved in the first phase of the continence care pathway; and 2) specific education and training curricula are developed for nurses to specialise in continence care. Ultimately, whoever takes over the initial assessment and treatment phase from GPs - be that a specialist nurse or a community worker well trained in incontinence - has to be educated on what, how and when to use the different treatment options for incontinence and to develop the competence to guide persons with incontinence to specialists where appropriate.

Summary of GFI thematic groups

Nurse empowerment and education: stakeholders participating in the thematic group on nurse empowerment and nurse education underlined four main barriers to full empowerment of nurses for better case management: lack of educators; no appropriate curricula for undergraduate nurses and specialized nurses in many countries and no corresponding professional certification; little information on available treatment/containment options; and lack of attention to incontinence in existing nurse education/training curricula. At the same time it was recognised that a number of best practices in nurse empowerment and nurse education exist today - such as the urotherapist group in Sweden and the accredited Nurse Continence Advisor education program at university level in Canada - which could be regarded as input to models for many other countries in the world. Overall, stakeholders agreed there is an urgent need for more training of healthcare professionals on continence care. In particular, there is a need to: clarify the different needs for different levels of education; discuss what competences nurses at different levels should have; develop a comprehensive standard assessment and certification system for specialist nurse training; and develop appropriate training content for both urinary and faecal incontinence.

Training of caregivers is insufficient; there is good access to products; but poor knowledge in how to use them.
GFI participant, USA

There are currently no university level courses on incontinence.
GFI participant, Slovakia

There are no statistics on the number of qualified nurse practitioners; both doctors and nurses need more training to better deliver their services along the patient’s pathway.
GFI participant, Portugal

All registered nurses could potentially be allowed to perform initial assessment and treatment, if given a chance to invest more in training on continence care.
GFI participant, United Kingdom

Integrated care: stakeholders at the GFI called for an inter-disciplinary approach to address the care needs of patients. They highlighted the lack of communication across professions, between the latter and IT providers and within members of the same teams of care professionals as major barriers to integrated services. The lack of information provided to patients about how the local system for continence care works (and where the gateway to access it is) was also emphasised as a crucial issue.

The focus groups reviewed best practice examples notably on: how nurses came together to better organise themselves; how municipalities cooperate with IT providers and health professionals for data sharing; and how integrated ambulatories on incontinence with GP, nurses and specialists have been established in some European countries. Furthermore stakeholders highlighted identifying a ‘case coordinator’ as an important step to link all phases along the care pathway and avoid gaps in the provisions of services.

Silo thinking is evident when incontinence is being treated at the same time by the Ministry of Health and the Ministry of Labour and Social Policy.
GFI participant, Poland

The main gap is the lack of integration between different ‘care networks’ in the same territory.
GFI participant, Italy
Self-management: stakeholders in this thematic group highlighted the important role of self-management in: helping people live with incontinence; adjusting to the disease; and easing the burden on health professionals, carers and society. Stakeholders identified pelvic floor, physical exercise, diet and lifestyle changes, e-health apps, and high quality incontinence products as key self-management tools. A clear precondition for the uptake of such self-management techniques is the prior dissemination of information on how to use them, e.g. by developing online platforms and tutorials, empowering healthcare professionals to teach patients and creating anonymised patient helplines. A second precondition is the development of a system which enables patients to have access to the right products according to their specific physical needs, rather than just based on affordability.

The Optimum Continence Service Specification: A Pathway for Change

Almost all national delegations and international stakeholders responded positively to the question if the Optimum Continence Service Specification provided a useful instrument to improve the organisation and delivery of care in their countries. The scientific study was perceived by country delegations as a valuable instrument that will help:

- Raise awareness of incontinence and continence care among the general public and in policy and stakeholder circles (incl. first among patient organisations in other disease areas);
- Engage in a dialogue with key policy and decision-makers and inspire/initiate change;
- Facilitate reflection on how to fund care options that take into account the specific patient profiles;
- Build support and awareness for incontinence as a health and social care priority;
- Develop national/local continence care pathways and promote adherence to available clinical guidelines.

The main message of this edition of the GFI was that change is possible and that there are many solutions at hand in order to improve the quality and delivery of continence care services, without adding extra costs to healthcare systems. The contributions of all the national representatives attending the 5th edition of the GFI demonstrated what can be achieved by working together. It is hoped that the discussion summarised here will inform and inspire the development of initiatives that will improve the delivery and organisation of continence care, to achieve better care, better health.

Note to the Editors

National delegations represented at the 5th GFI included the following countries: Austria, Belarus, Belgium, Canada, China, Croatia, Denmark, Estonia, Finland, France, Germany, Hungary, India, Italy, Japan, Latvia, Lithuania, the Netherlands, Norway, Poland, Portugal, Russia, Slovakia, Slovenia, South Korea, Spain, Sweden, Switzerland, United Kingdom, Ukraine and the United States of America.

June 2014
The International Continence Society welcomes the efforts of the GFI to define and address the issue of service provision across a variety of healthcare jurisdictions. As a multi-professional society we are pleased to see the involvement of the multidisciplinary team in services and recommendations for training of both regulated and unregulated staff in assessment and management of this distressing condition.

International Continence Society (ICS)

CNCA was pleased to see the call for accredited education programs, such as the McMaster University Nurse Continence Advisor (NCA) education program which has been critical in establishing and expanding the role of the NCA across Canada.

Canadian Nurse Continence Advisors (CNCA)

E.D.E. welcomes this international exchange of knowledge and experiences and is very happy to be an active part of it. Policy makers in other countries focus differently on the challenges ahead. They help us to find the right focus in our own countries.

European Association for Directors and Providers of Long-Term Care Services for the Elderly (E.D.E.)

The GFI represents one of the few international events providing the opportunity for a qualified exchange of experiences among stakeholders with different background (i.e. not only coming from the academia) on such a crucial topic like incontinence.

Eurocarers

Participating in the 5th GFI was remarkable. Having the many different countries and policy makers there was an accomplishment in itself! But the level of involvement and caring from everyone was even more remarkable. Every country has such a different way of viewing incontinence and utilizing its resources. From the nursing perspective, there is such variability in roles and education in each country. With nursing being at the centre of care, increasing their education in incontinence, their interest and their involvement in the care of incontinent individuals is vital. It was a privilege for SUNA to be a part of this!

Society of Urologic Nurses and Associates (SUNA)

It was very clear from the active discussions that the Optimum Continence Service Specification had a strong resonance across different professional groups and different countries. The Specification is a much needed and helpful contribution to the development of integrated incontinence services and I was delighted to have had the opportunity to be part of this excellent event.

European Health Management Association (EHMA) – GFI Thematic Group Chair

The Fifth GFI has shown which important ideas can be realised if research, practice and industry are working together. We are sure that this cooperation will contribute to further improvements in long term care.

European Centre for Social Welfare Policy and Research

In older people, urinary incontinence does not come alone, so it should be assessed and managed using a multidimensional approach and functional outcomes.

European Union Geriatric Medicine Society (EUGMS)

At the GFI we have understood how the burden of incontinence can be lessened by adopting a smarter approach to care: self-management and patient education are key components of this new model and cost-effective solutions in the longer term.

John Bowis, GFI Thematic Group Chair