SURGICAL CARE FOR FEMALE URINARY INCONTINENCE

Research protocol

BACKGROUND AND RATIONALE

Urinary incontinence (UI) is the complaint of involuntary loss of urine and includes different types of UI with different underlying aetiologies. Stress UI is defined as loss of urine on effort, physical exertion, or on sneezing or coughing. Urge UI is the loss of urine associated with urgency. Overactive bladder syndrome (OAB), which includes urge UI, is usually accompanied by frequency and nocturia, with or without urge UI.[1]

The prevalence of at least some degree of UI shows a wide range. In the UK, 30 to 40% of women are estimated to be affected by UI.[1-4] UI has a significant impact on quality of life,[5-9] affecting physical and social activities, confidence and self-perception.[10] Research comparing the impact of chronic conditions on quality of life found that UI ranked 3rd out of 12 conditions, behind Alzheimer's disease and stroke.[11] UI is also associated with depression,[12, 13] falls,[14] and admissions to nursing homes.[15]

Treatment

In the UK, despite major national initiatives in the last decade, the quality and availability of continence services remains poor, variable and inequitable. The burden on secondary care resources (economic and clinical) is increasing due to demographic changes and higher rates of referrals. These trends in demand coincide with an increased use and improved effectiveness of procedures such as synthetic tapes, Botulinum toxin-A injections and sacral neuromodulation. These and all other surgical approaches / invasive procedures for different types of UI are hereafter referred to as "surgery".

The landscape of UI care is rapidly changing. Across the healthcare system, there is an aspiration to shift services for women with UI from secondary to primary care in order to reduce costs and improve care quality. At the same time, it is unclear whether the current level of provision in surgical services for UI is appropriate. A recent national audit suggested that the overall rate of surgery for UI is lower than expected.[16]

The integrated service model for continence care set out in the Department of Health's publication "Good practice in continence services", indicates that 80% of continence management could be delivered by clinicians within primary care.[17] However, in the UK, the care for women with UI is dominated by hospital-based, specialist services, partially due to lack of expertise and interest for continence care among most general practitioners.[18] First-line treatments for UI include lifestyle changes, pelvic floor muscle training, bladder training and medication. Surgical treatments are indicated when first line treatments are not tolerated or proven ineffective.[19] There are unanswered questions about assessment and treatment of women before referral, the duplication of treatment in each care environment, and the appropriate delivery of secondary-care interventions.[20] More than 50% of patients referred to secondary care are reported not to have received any treatment in primary care.[21]

There is evidence that surgical treatment for incontinence has been increasing in England,[22, 23] most likely due to the introduction of minimally invasive procedures. For the treatment of stress incontinence, the use of synthetic mid urethral tapes such as TVT/TOT increased (with 12,000 procedures per year), while colposuspension procedures decreased between 2000 and 2012. For overactive bladder and urgency UI, there was a significant increase in the use of Botulinum toxin-A and sacral neuromodulation, coinciding with a decline in the recorded use of "clam" ileocystoplasty and ileal conduit. However, it remains unclear whether the current level of provision in surgical services for UI is appropriate with concerns that not all eligible patients have equitable access to these procedures.[16]

There are also concerns about specific populations. For example, whilst it has been shown that the minimally invasive mid-urethral sling procedures are safe and effective in older women[24] and can be performed often as a day-case procedure, these procedures are less frequently used in older than in

younger patients.[18, 25] It is likely that there is also suboptimal care for women from different ethnic and socio-economic backgrounds[26, 27] and other vulnerable populations such as women with dementia.[28]

Recent guidelines recommend that services for women with UI should be coordinated within "regional clinical networks" to ensure that all recommended treatment options and necessary expertise can be provided. There is also considerable uncertainty about whether the level of provision for surgical services is uniform across regions and providers in England. Variations in care provision may also depends on the availability of UI services. A recent survey of the availability of specialist UI services has demonstrated that there is variable distribution of urogynaecologists with subspecialty training, dedicated teams to manage repeat surgery, and availability of various surgical care treatments across the UK.[21]

Patients' perspective
There is limited research on what treatments women with UI want themselves and what factors have an impact on their preferences. Moreover, there is no research to date on how GPs decide when women need to be referred and how clinicians decide whether or not surgery is helpful. Although UI can have substantial impact on quality of life, there is evidence that many women with UI underreport or delay seeking treatment for several years after the problem has become bothersome,[29] leading to high levels of unmet need for incontinence services.[3] For example in the UK, only about a quarter of women consult a doctor about their symptoms.[2] Delayed health seeking and underreporting might be due to the belief that these symptoms are normal after childbirth or in older age, and to a lack of awareness of available treatment options.[30, 31] A study in women who were referred to a urogynaecological outpatient clinic demonstrated on the other hand that women with UI are keen to have the treatment with the highest chance of long-term success, even if this is an invasive procedure.[32]

Clinical coding
It is recognised that UI and related procedures are poorly coded in electronic clinical records. Therefore, before existing databases such as Clinical Practice Research Datalink (CPRD) and Hospital Episodes Statistics (HES) can be used to study service provision in primary and secondary care, a detailed coding framework needs to be developed and validated that aims to overcome these deficiencies as much as possible. This methodological work is not only an essential preparation for data analysis, but it will also guide recommendations on how diagnoses and procedures related to UI can be better recorded into electronic databases in the future.

AIMS AND OBJECTIVES

The aim of the project is to improve the delivery and organisation of surgical services for women with UI in England. The project will assess the availability and use of surgical services for UI across England and identify factors that explain observed variation in use, including the impact of data issues, patients' experiences and expectations, clinicians' judgment, and organisational and contextual factors. This work will demonstrate how equity of access and quality of care can be improved.

The specific objectives are captured in five work packages (WPs). We will analyse existing primary and secondary care datasets and collect data from patients (using in-depth interviews) and clinicians (using case-vignettes).

Objective 1: Methods development
- To assess the consistency, completeness and accuracy of diagnostic and procedure coding for UI in existing electronic datasets (WP1).
- To develop a coding framework for UI allowing for divergent coding practices among providers (WP1)

Objective 2: Availability, delivery and quality of services
- To assess variation between NHS Clinical Commissioning Groups, Local Area Teams and Clinical Senates (or other relevant regional units) in rate of surgery for UI (WP2).
- To examine the impact of supply side factors (e.g. primary care characteristics and availability and delivery of secondary care services) on local surgical rates (WP2).

Objective 3: Understanding patients' experiences and expectations
- To explore the impact of UI on women's lives and whether and when it is perceived to be a medical problem (WP3).
- To collect women's own accounts of experiences and expectations of surgical and non-surgical treatments and outcomes, including the many different values that women draw on (WP3).

Objective 4: Understanding the determinants of referral and surgical treatment
- To identify determinants of outpatient referrals and surgery, using a linked primary-secondary care dataset (WP4).
- To explore the relative importance of specific patient characteristics for clinicians in their treatment decisions, using case vignettes (WP5).

Within all WPs, there will be further work to evaluate how findings vary according to age, economic deprivation, ethnicity and type of procedure.

METHODS

This is a multi-methods project, including analyses of existing primary and secondary care datasets, qualitative research of patients' experiences and expectations and a study of clinicians' decision making.

WP1: Methods for the analysis of existing datasets
Objective 1: Methods development
- To assess the consistency, completeness and accuracy of diagnostic and procedure coding for UI in existing electronic datasets.
- To develop a coding framework for UI allowing for divergent coding practices among providers.

Data sources
The Hospital Episodes Statistics (HES) database contains patient demographics, administrative data, and clinical information for each episode of inpatient care. Diagnostic information is coded using the International Classification of Diseases 10th revision (ICD10) and operative procedures are coded using the UK Office for Population Censuses and Surveys classification, 4th revision (OPCS4). Preliminary explorations of HES have revealed that multiple diagnostic and procedure codes can be used to identify patients with UI and relevant procedures.[35]

Development of coding framework
The Clinical Practice Research Datalink (CPRD, formerly the General Practice Research Database) is a primary care research database which collates anonymised patient data using Read codes (used to record symptoms, diagnoses, processes of care) and Multilex codes (used to record information on drugs) from over 600 GPs codes in the UK, covering 9% of the population with CPRD, with about 50% of these being linked to HES. It is representative of the general English population, deemed "up-to-standard" for research purposes and widely used in epidemiological and health services research. A systematic review of 49 studies on the accuracy and completeness of diagnostic coding in CPRD concluded that while most of the diagnoses coded in the CPRD are well recorded, researchers need to consider how optimise identification of clinical events for the condition of interest.[36] A study using the THIN database, a primary care database comparable to the CPRD, has demonstrated that a workable code list to identify patients with UI can efficiently be produced using an explicit stepwise compilation process linking relevant clinical terms with the entries in the complete list of Read and Multilex codes.[28,37]

In this WP, we will consider the definitions of diagnoses and procedures to identify potentially relevant codes in each dataset. For the HES database, we will first use a "forward and backward" searching strategy. The forward searching step starts with a list of ICD10 and OPCS4 codes that are compiled iteratively by the clinical and methodological members of the Research Team. The backwards strategy then explores whether records found on the basis of the pre-specified ICD10 codes contain additional relevant OPCS4 codes that were not pre-specified and a similar exercise considers additional ICD10 codes in records found on the basis of the pre-specified OPCS4 codes. Second, we will assess the frequency with which all these potentially relevant codes have been used and explore

the consistency of diagnosis and procedure codes within records of individual patients. Third, the variation in consistency of diagnosis and procedure codes among providers will be explored to identify providers that have divergent coding practices. We have demonstrated that this strategy for using HES data has the potential to produce a coding framework creating groups of patients who are homogeneous with respect to diagnosis, prognosis and treatment.[38] For the CPRD database, we will start with the code list that was compiled previously.[28] We will then test this existing code list by evaluating the consistency between diagnostic and treatment codes and the temporal consistency of coding within records of the same patient. If required the original code list will be amended and / or expanded.[37]

Further methods development will be carried out with the linked CPRD/HES dataset for an accurate assessment of primary care and referral patterns (WP4) and variations of care at regional and provider level (WP4). The clinical codes in the CPRD will be mapped to codes used in HES to allow an assessment of the comparability of the data in both databases.[36, 39] Prior studies utilising linked datasets have used the NHS Health and Social Care Information Centre's NHS Clinical Terminology Browser for the mapping.[39] Regarding the measurement of risk factors, a study on the recording of ethnicity in CPRD and HES concluded that completeness of ethnicity field is high since 2006 and that there is high concordance across the two data sources.[40] However, other variables may need further work. For example, while the completeness of BMI in CPRD increased over time, imputation methods may be needed to reduce the impact of possible BMI misclassification in the data.[41]

Assessment of coding framework
The output of this WP will be a coding framework for the HES and CPRD databases that will allow for divergent coding process among providers. The suitability of these databases for research will be tested through an assessment of the consistency of codes in a variety of ways:

- consistency between diagnostic and treatment codes within single CPRD and within single HES records.
- temporal consistency between records within CPRD and within HES that belong to the, same person.
- agreement of coding – either diagnostic or treatment codes – between the CPRD and HES database.

WP2: Geographical variations in surgical treatment
Objective 2: Availability, organisation and quality of services

- To assess variation between NHS Clinical Commissioning Groups, Local Area Teams and Clinical Senates (or other relevant regional units) in rate of surgery for UI.
- To examine the impact of supply side factors (e.g. primary care characteristics and availability and organisation of secondary care services) on local surgical rates.

Data sources
We will use HES data to estimate standardised rates of surgery within regions covered by Clinical Commissioning Groups and other relevant regional NHS structures and bodies. Using multilevel regression models, we will determine the extent of systematic variations in rates of surgery and associations with contextual characteristics.[42] The analysis will differentiate between types of UI and surgical procedures (e.g. synthetic tapes, colposuspension, botulinum toxin A and sacral nerve stimulation) as well as between primary and repeat procedures.

Coding
As explained earlier, a list of diagnostic codes based on the ICD10 and treatment codes based on the OPCS4, compiled in WP1, will be used to identify women with UI as well as the surgical treatments they have received. Previous work carried out by the applicants has demonstrated that the HES database can be used successfully to study the treatments and outcomes of women with UI.[35]

Regional analysis
Patterns of surgical care will be summarised among Clinical Commissioning Groups, Local Area Teams and Clinical Senates / Strategic Clinical Networks. The socio-economic characteristics will be captured using the overall Index of Multiple Deprivation, which is derived from 32482 geographical areas, known as super output areas, and combines factors related to income, education, employment, health deprivation disability, crime and living environments, and barriers to housing and services.

We will use information from a survey of female UI services across England carried out by the British Society of Urogynaecology in 2014 in combination with the results of the annual NHS and RCOG Workforce survey to map the availability of surgical services within NHS regions and providers. The survey that was carried out in 2014 includes information on the availability of services in each unit, whether there is a dedicated (and one-stop) clinic for UI, and the provision of information to patients.[21] We will also use measures of patient-reported access to general practice, obtained from the GP Practice Survey.[43] This annual survey invites adults registered with a GP in England to complete a validated questionnaire about their experiences and satisfaction with their practice. Individual responses are aggregated by age and sex to ensure representativeness of each practice's registered population. For example, the responses to the GP Practice Survey have been used to study the influence of access to general practices on A&E attendance.[44]

Statistical methods
Indirectly age-standardised procedure rates will be derived for the geographical regions defined above by dividing the observed number of procedures by the number expected if the region had the same age-specific rates as England, and then multiply this ratio by the English procedure rate. Reference female populations will be aggregated from 2011 Census population data.

Variation in the standardised rates for the geographical regions will be shown using funnel plots which will test whether the regional rates differ significantly from the national rate for England. The amount of excess variation (i.e. non-random) between the age-standardised procedure rates will be estimated using multilevel Poisson regression, including information on gynaecology units and GP practice characteristics. A variance-components model will be used to estimate the variance between the geographical regions. Region characteristics, including the percentage of the population from a non-white ethnic background will be added to the multilevel Poisson model to determine how much of the regional variation they explain.

WP3: Patient expectations and experience
Objective 3: Understanding patients' experiences and expectations

- To explore the impact of UI on women's lives and whether and when surgery is perceived to be a treatment option
- To collect women's own accounts of expectations of surgical and non-surgical treatments, experiences and outcomes, including the many different values that women draw on

Context
This qualitative research, informed by social science, will provide knowledge that the quantitative research in the other WPs cannot.[27, 45] Complementing the large-scale datasets, it will explore a range of different factors by "giving voice" to women with stress UI or urge UI/overactive bladder who are considering surgical treatment through extended semi-structured interviews. The strength of this work is that it will analyse individual accounts to explore how women make sense of their incontinence problems in relation to notions of health and illness and the emotional and affective dimensions that give these testimonies particular significance. It will elicit any fears or expectations that women have, their accounts of the treatment options that were offered, and how they experienced the process of decision-making, especially with respect to surgery. Analysis of such experiences will not only supplement the quantitative analyses but will also provide first-hand authoritative accounts that have the potential to influence policy-making and everyday clinical practice. The work package will be led by an experienced qualitative researcher who has had extensive experience in collaborating with quantitate researchers and liaising with NHS.

Theoretical framework
Although already only a limited amount of qualitative research has been carried out among women with UI[27, 32, 46-49], a broader narrative review of the patient experience literature within the social sciences will serve to map out the issues incontinence raises in common with other conditions, including issues related to shame, embarrassment and stigma; gender, identity and sexuality, related to impact on social relationships, work and mobility, related to experiences of care, medicalisation of the female body, in the context of the invasive nature of surgery as a possible treatment option. These higher-order topics will generate the analytical themes that will later be used to complement the more descriptive codes derived from content analysis of the interviews.

The topic guide will be informed by the results of the other WPs and benefit from the entire Research Team, especially drawing on the input from the public and patient. Rather than consisting of direct informational questions, the interviews will be sufficiently open and flexible to ensure participants are able to talk at length about issues that most concern them. The overall approach will be to encourage women to describe the experiences of incontinence and related medical and surgical interventions within narrative accounts of their everyday lives. This will ensure their testimonies have the potential to provide a rich holistic overview of the broader issues. The accounts will offer insights to supplement and inform other WPs, and have the potential to convey an empirical veracity that can help influence policy making and organisation of surgical services.

Sampling
Up to 60 face-to-face interviews will be conducted with participants purposively sampled in order to achieve maximum variation, rather than representativeness, allowing the study to explore a full range of women's experiences and accounts. Patients, who are referred for the first to a gynaecology outpatient clinic with stress UI or urge UI/overactive bladder will be invited to take part in the study at selected hospitals across England. With the assistance of clinic administrative staff, ensuring that the Research Team cannot access confidential patient details, potential interviewees will be selected according to a simple set of criteria (such as age, ethnicity and severity / type of UI), and sent an introductory letter, information leaflet and a pre-paid reply envelope. It will be up to the women to provide contact details to the Research Team. As a result, only those women who wish to take part will have any further contact with the project.

Data collection
Upon receipt, follow-up communication will allow for the arrangement of the interview at a suitable time and location for the participant, reassuring the individual that the research will remain confidential and it will not affect the care that they receive and providing an opportunity to ask further questions. In order to further ensure that women feel a sense of trust and respect, the interviews will be conducted either in their homes, a dedicated room in the relevant hospital, or anywhere else they feel most comfortable.

To ensure all sensitivities are considered, the Research Team will take the opportunity to have informal conversations prior to data collection with members of the Patient Advisory Group who will be able to offer insight into the possible issues that might arise. Pilot interviews will be conducted with carefully selected patients who will be forewarned that we would appreciate their feedback afterwards regarding the sensitivity of some of the topics. In addition, the patient informal sheet will include contact details of relevant NHS resources and support groups, such as the Association for Continence Advice.

Prior to the interview itself written consent will be obtained. Interviews will be recorded, and transcribed verbatim. The transcripts will have all identifiable information redacted, to ensure that the data will be completely anonymised prior to analysis, and then entered into the qualitative data management software Nvivo 10 for coding.

Analysis
Analysis will be thematic and iterative, based initially on descriptive codes, and then analytic codes mentioned above. To ensure reliability, a sample of data will be coded blind by at least two researchers. Emerging themes and preliminary findings will be discussed by the entire project team, and presented to the public and patient representatives to help further refine the analysis and ensure it remains relevant and true to the experiences of the women themselves.

Ethics
Data handling and storage will follow national and institutional guidelines relating to protection and confidentiality at all times, as reflected by the overall description of the WP.

WP4: Primary care and referral patterns

Objective 4: Understanding the determinants of referral and surgical treatment

- To identify determinants of gynaecology outpatient referrals and surgery, using a linked primary-secondary care dataset

Data sources

We will use the CPRD linked to HES to study determinants of referral to secondary care and progress to surgical treatment. We will use regression models including patient characteristics, such as type of UI, age, BMI, ethnicity, socio-economic deprivation, and patterns of prior care.[41] This WP will allow us to contrast patterns of referral with patterns of surgical treatment and to study to what extent inequity in access to surgical services originates in primary or secondary care.

Determinants of referrals and surgery

We will include all women older than 18 years diagnosed for the first time with a diagnosis of stress UI or urge UI/overactive bladder in primary care according to the coding framework that we will define in WP1 in the ten most recent years of data (e.g. from 2002 to 2012). A woman will be considered to be diagnosed for the first time if a similar diagnosis could not be recognised in the preceding two years. We will measure comorbidity by identifying the number of different drug classes prescribed in CPRD records of primary care[28] and the diagnoses included in HES records of secondary care.[50] Ethnicity and socio-economic deprivation will be derived from CPRD data for all women and compared with HES data for those who are referred to secondary care.

Analysis

The included cohort of women will then be followed up from the date of the first incontinence diagnosis. Care provided in primary care (especially drug prescriptions), referrals to gynaecological outpatient clinics and care episodes in secondary care (e.g. visits to gynaecology outpatient clinic, day-case and hospital admissions, and surgical procedures) will be analysed from a time-to-event perspective.

We distinguish three types of outcomes: treatments given in primary care, referral to a gynaecology outpatient clinic and surgical treatment.

Statistical methods

We will start using descriptive statistics to explore the number of GP visits and treatments the women received in primary care in the first year following the date of the first incontinence diagnosis. In a second step, patients will be followed up to describe the rate of referral to gynaecological outpatient clinics using Kaplan-Meier methods. The rate of referral will also be expressed as the number of referrals per person-year at risk. The determinants of referral to a gynaecology outpatient clinic will be identified using multilevel Cox (or Poisson) regression considering the general practice as a random effect. We give special attention to impact of the type of UI, age, socio-economic deprivation, ethnicity, comorbidities, and first treatment at the time of diagnosis.

In a following step, the determinants of surgical treatment will be explored in women who were referred to a gynaecological outpatient clinic, again first describing the rate of surgery in the first year following the referral and then exploring the impact of the determinants defined above using either multilevel Cox or logistic regression, depending on whether surgical rates will be defined as rates or proportions. The choice between using Cox or logistic regression depends on whether a time-to-even or a cross-sectional approach seems most appropriate.

WP5: Clinician decision making

Objective 4: Understanding the determinants of treatment decisions

- To explore the relative importance of specific patient characteristics for clinicians in their treatment decisions, using case vignettes

Context

This WP will contribute to a better understanding of determinants of variation in surgical treatment, and whether these accord with patient expectations. Using simulated patients described by case vignettes has been used to measure variation in clinicians' approaches to the diagnosis and treatment of patients with similar health problems.[51, 52] These studies are considered to be a more cost-effective

way of studying how clinicians respond to specific characteristics of their patients when making decisions than using medical records or standardised patients.[53-55]

Prof Van der Meulen led a Dutch study that included 32 case vignettes describing the clinical profiles of elderly patients with aortic stenosis to all cardiologists in the Netherlands.[56] For each clinical case, the respondents were asked to indicate how likely they were to recommend surgical treatment. The results demonstrated that there were systematic differences among groups of cardiologists in their inclination to recommend surgical treatment as well as in the way their recommendations were influenced by the patients' characteristics. A follow-up study comparing the results of a study using case vignettes and observations in actual patients found a strong agreement which supports the validity of the case-vignette approach.[57] For this WP, we propose to use a similar technique to study how gynaecologists make decisions about whether they recommend surgery or alternative treatments for women with UI.

Although they follow similar principles in their design and are related to conjoint analysis, case vignettes are different from Discrete Choice Experiments (DCE) in that they only present a unique scenario to respondents and ask them to make a decision (usually binary) based on the characteristics of the depicted scenario. DCEs would have been appropriate if treatment options for women with UI could be described precisely, both in their characteristics and their consequences. However this is currently not the case, therefore the team has opted for case vignettes.

Design of the case vignettes
A list of patient characteristics will be extracted from national guidelines, published literature, and the results of the analysis other WPs. Clinicians and public and patient representatives in the Research Team will be asked to assess each of the patient characteristics to determine whether it is likely to influence clinicians' decisions about surgery for incontinence and whether it should be included in the set of vignettes. We envisage that these characteristics may include clinical factors including type (stress or urge / overactive bladder) and severity of UI, and comorbidity and (the results of) previous treatments in primary and secondary care as well as demographic factors including age, socio-economic status, and ethnicity.

Including these characteristics, a series of case vignettes will be designed following a fractional factorial design based on the principles of experimental design theory, to ensure the absence of collinearity between the patient attributes, ensuring that we can study the effects of their characteristics on treatment decision with a limited number of vignettes. The vignettes will be presented as much as possible following the structure of a routine case presentation with the important characteristics highlighted. The gynaecologists will be asked to indicate whether they would recommend surgery or alternative treatments (e.g. physiotherapy or other conservative treatment). We envisage, based on our previous research and that of others that up to 30 – but most likely fewer – cases will be needed. We will add a number of extra case vignettes ("hold out profiles") which will be used to evaluate whether the recommendations given for these four extra case vignettes can be predicted using the statistical model that will be derived from the series of actual vignettes.

Survey
All gynaecologists who are member of the British Society of Urogynaecology will be invited to participate. A response rate of at least 50% is expected based on experience in similar studies. The survey will be delivered electronically. Non-responding gynaecologists will receive two reminders.

Statistical analysis
Latent class regression estimation of the "weight" that clinicians place on each characteristic will produce regression equations, each of which represent a "latent class" of clinicians with a particular "practice style".[58] This is a regression technique that estimates a number of regression equations in which the recommendation score of the gynaecologists is the dependent variable and dummy variables representing the level of the patient characteristics the independent variables. The number of classes that optimally explains the heterogeneity in the responses will be determined by statistical criteria.

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