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DAILY-LIVING SELF-MANAGEMENT OF PERSISTENT URINARY INCONTINENCE: COMPARISONS BETWEEN THE SELF-MANAGEMENT PRACTICES OF PEOPLE WITH UI AND THE RECOMMENDATIONS OF CONTINENCE NURSE SPECIALISTS

Hypothesis / aims of study

The aims of this study were to:

- 1. Describe self-management strategies as identified by people living with urinary incontinence (PLWUI)
- 2. Identify the recommendations Continence Nurse Specialists (CNSs) give to clients for management of UI
- 3. Compare the advice given by CNSs with the current self-management practices of working-age women, older women and men with UI

The findings of this study informed the design, development and evaluation of client-advice materials and education materials for health professionals.

Study design, materials and methods

This descriptive and comparative design used a mixed methods approach to investigate self-management strategies in adults with UI (PLWUI Study) and management advice recommended to clients by CNSs (CNS Study). A survey was used to collect data from both groups. To facilitate more in-depth responses semi-structured interviews were used in the PLWUI study and open-ended questions were incorporated into the CNS survey.

Both survey tools were developed by the research team to meet the needs of the study. A conceptual framework guided the development of the questionnaires. Revisions to the questionnaires followed an initial pilot and consultation with a statistician. The final instruments had two major sections: 'problems that were difficult to manage' and 'strategies for self-management'. These sections were mirrored in both surveys to enable comparisons between PLWUI and CNS responses. The instruments were self-administered.

In the PLWUI study the sample included working-age women (18-65 years), older women (over 65 years) and men who had UI for more than 6 months, were living independently in the community and were English speaking and able to self-administer the survey. Participants were recruited via continence clinics and print advertising. CNSs were identified via conference attendance and membership of "Continence for Nurses". They were then contacted directly by post and asked to participate by completing the survey.

Results

In total 104 working-age women, 103 older women and 103 men completed the PLWUI survey and 86 CNSs completed the CNS survey.

Results showed that the problems PLWUI found most difficult to manage were those occurring frequently, publicly, attracting social stigma and over which they had no control. CNSs accurately identified problems that PLWUI found most difficult to manage. The PLWUI study revealed some self-management strategies that were used frequently by all participants regardless of gender or age. The most frequent strategies used common to each group were going to the toilet as soon as you get the urge, getting up at night to go to the toilet, learning more about UI and keeping bowels regular. There were significant differences across the groups in the types of strategies used and the frequency with which they were used. For example: older women were more likely to limit business and leisure travel; working-age women were more likely to tighten their pelvic floor muscles when in danger of leaking and; men were less likely to use pads and aids in the management of their UI.

Comparing data across the two studies reveals some discrepancies between the actual self-management practices of PLWUI in the community and the advice given by nurses to clients of continence services. These differences were most stark in the domain of strategies associated with fluid intake. On the whole participants reduced their fluid intake and avoided fluids when they were out whereas CNSs rarely or never advised this practice. Alternatively CNSs recommended that clients reduce their caffeine and alcohol intake whereas this was rarely practised by PLWUI. Reponses to strategies related to toileting practices revealed similar discrepancies. CNSs rarely advised clients to go to the toilet once experiencing the urge and never advised that PLWUI keep their bladder empty when they are out. PLWUI, however, practised both these strategies often.

Interpretation of results

Although many of the participants in this study had not used a continence service, the discrepancies between professional advice and self-management practice nevertheless indicates an important theoretical divide between the purpose and intention of CNS advice and the actual strategies adopted by PLWUI. Analysis of the interview data suggests that the strategies used by PLWUI are intended to enable normal daily-living, with little disruption to important daily routines. Although CNSs are cognizant of this fact, the focus is primarily to provide best practice advice to the client. Therefore, advice given by the CNS, if evaluated by the client as not fitting with their normal lifestyle is less likely to be adopted.

Concluding message

These results inform the wider objective of the study which is to develop advice materials for PLWUI and education materials for CNSs. The materials will therefore reflect the importance of empowering clients' to manage UI in an informed way, acknowledging the contextual nature of daily self-management. More sophisticated advice and support is needed to assist clients to plan and develop personally-tailored short, medium and long term daily living management strategies.

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HUMAN SUBJECTS: This study was approved by the Griffith University Human Research Ethics Committee (and seven hospital HRECs) and followed the Declaration of Helsinki Informed consent was obtained from the patients.