Measuring the Psychosocial Impact of Continence Management Technologies

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Urinary incontinence (UI) poses problems for millions of people of varying ages worldwide. For example, in Canada, approximately 1.5 million people are affected by UI (Swanson et al., 2002). There are important psychosocial impacts for people with UI that have significant effects on quality of life. Consequently, many forms of intervention have been developed to aid in the management of incontinence. These include a range of surgical procedures (e.g., sling procedures), behavioural instruction (e.g., prompted voiding), pharmaceutical methods (e.g., anticholinergic drugs), and assistive technology devices (ATDs).

ATDs may be defined as any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to maintain or improve functional capabilities (Bausch et al., 2005). ATDs are available to aid in continence management. Among the most commonly used devices are removable and reusable devices such as pessaries, vaginal insert devices, and continence guard technology. These devices provide structural support to the urinary system, and aid the urethra and urethral sphincter in performing their proper functions. For men, artificial urinary sphincters are a common treatment for incontinence following a prostatectomy. Once implanted, the sphincter provides adjustable support for the urethral sphincter and restricts any unwanted urine leakage. In addition to insert devices, external aids are commonly used in treatment. Reusable underwear and pad technologies absorb leaked urine, thereby preventing soiled clothing. These aids also mask the odour of urine and help promote social confidence and hygiene. Additionally, electrical stimulation devices are employed to assist in the management of incontinence. Electrical current is applied to the muscles of the urinary structures, promoting muscle strength and integrity. Finally, bio feedback devices incorporate sensors which relay information about the occurrence of muscle contraction to the device user. This design enables the user to gain control over their bladder function. Evidently, there are many devices to help manage incontinence in adults; however, their relative effectiveness has not been well established.

UI can have important impacts on psychological and social functioning, and has been associated with elevated levels of stress, feelings of powerlessness as well as isolation and depression. UI also serves as a formidable barrier to engaging in activities of daily living. A topic that has received scant attention in the research literature is the stigma associated with UI. Individuals are stigmatized when they possess, or are thought to possess an attribute that conveys a social identity that is devalued (Crocker et al., 1998). Persons with UI are commonly stereotyped as frail, dependent, incompetent and old (Mitteness et al., 1995). The fear of being stereotyped often prompts individuals with UI to conceal identifiable aspects of UI in social settings, and to avoid ATDs and/or fail to comply with their treatment regimens (Shaw et al., 2001).

The numerous effects of UI on a person’s psychological and social wellbeing make it challenging to measure the relative success of a particular treatment. For example, it is prudent to ask oneself if reducing the number of leakage episodes constitutes a better treatment success than a client’s own perception of dryness. The former is an objective measure, acquired by using a pad weight test (for example), while the latter is a subjective measure.

This article gives a progress report on a project entitled "Development and Validation of a Questionnaire to Measure the Psychosocial Impact of Assistive Technologies for Continence in Elderly Individuals", funded by the Canadian Institutes for Health Research (CIHR; Grant CUK 94353). The project is being done in collaboration with New Dynamics of Ageing Phase 2 CRP – Full Phase entitled, “Tackling Ageing Continence through Theory, Tools and Technology TACT3” (Principal Investigator: Eleanor van den Heuvel, Brunel University). The project has three major objectives: (1) do a literature review to examine the effectiveness of current ATD interventions for adults 65 or older who have incontinence; (2) do a literature review to evaluate instruments for assessing the outcomes of UI intervention, including their sensitivity to psychosocial factors such as stigma and the use of ATDs; (3) investigate how a well researched instrument, the Psychosocial Impact of Assistive Devices Scale (PIADS), might be adapted specifically for measuring the impact of continence ATDs.
Effectiveness of Continence Technologies

Fourteen published research studies met the criteria for selection for the review. A standardized approach to evaluating strength of research evidence was applied to each report (cf. Jutai et al., 2009 for details about the methods). In brief, studies were evaluated using the Downs and Black (1998) instrument, a 27-question checklist for assessing the methodological quality of both randomized controlled trials and nonrandomized studies. Levels of study quality were then mapped to strength-of-evidence levels and used to formulate results. The following is a list of the best researched technologies for continence management (in parentheses are the number of eligible studies and the level of strength of evidence determined for each technology): (1) Electrical/magnetic stimulation (4; Strong); (2) Biofeedback (2; Moderate); (3) Artificial urinary sphincter (3; Weak); (4) Urinary insert (2; Weak); (5) Pessary (1; Weak); (6) Reusable undergarment (1; Weak); (7) Implantable urinary device (1; Weak).

Conclusions from the literature review are that the strongest evidence is for electrical/magnetic stimulation devices. The best available research has been done on medical devices. Very little outcomes research has been done on assistive devices as described above. There is a dearth of research evidence on the psychosocial impact of devices.

UI Intervention Outcome Measures

Ten outcome measurement tools, designed specifically for continence/incontinence met the study criteria for selection and review (Southall et al., 2011). Each measure was assessed for its psychometric and administrative properties, as well as for content linked to social- and self-stigma. The questionnaires included in the review were: Bristol Female Lower Urinary Tract Symptoms Questionnaire - BFLUTS (Jackson et al., 1996); Geriatric Self-Efficacy Index for Urinary Incontinence - GSE-UI (Tannenbaum et al., 2008); Incontinence Impact Questionnaire - IQ-7 (Shumaker et al., 1994); Incontinence Outcome Questionnaire - IOQ (Bjelic-Radisic et al., 2007); Incontinence Quality of Life Questionnaire - I-QOL (Wagner et al., 1996); International Consultation of Incontinence Questionnaire Urinary Incontinence Short Form - ICIQ-UI-SF (International Consultation on Incontinence Modular Questionnaire, 2006); Kings Health Questionnaire – KHQ (Kelleher et al., 1997); Male Urinary Symptom Impact Questionnaire - MUSIQ and Male Urogenital Distress Inventory - MUDI (Robinson et al., 2007); Urogenital Distress Inventory (UDI-6) (Shumaker et al., 1994); and the Stamey Urinary Incontinence Scale (Stamey, 1979).

The review found that the identified instruments are reasonably well researched, designed principally to assess the health-related quality of life impact of incontinence symptoms. They have not been used consistently or extensively in device effectiveness research. Their validity for evaluating the effectiveness (especially the psychosocial impact) of assistive devices is unknown. None of the measures completely and thoroughly assesses stigma.

Development of a New Instrument for Measuring Psychosocial Impact of Continence ATDs

Semi-structured interviews were conducted with elderly individuals who experience episodes of UI. Questions included: What technologies (i.e., devices and strategies) are used for continence management? What daily difficulties are encountered with continence management? What is the impact on daily life and significant other people? What are the best liked and disliked features of the technologies being used? What barriers are there to obtaining desired continence management solutions? Upon completion of the interview component, participants were asked to complete the PIADS questionnaire, and comment on difficulties using the scale. The PIADS is a 26-item self-report questionnaire for evaluating the impact of an assistive device on quality of life (Day et al., 1996; Jutai et al., 2002). Scores on the PIADS are summarized in three quality of life subscales: Competence (reflecting perceived functional capability, independence and performance); Adaptability (reflecting inclination or motivation to participate socially and take risks); Self-esteem (reflecting self-confidence, self-esteem, and emotional well being).

Most participants reported that incontinence was associated with high blood pressure, diabetes, and kidney disease, although UI sometimes appeared without an apparent underlying cause. Most participants used pads and did not discuss their continence problems with other people. Generally, participants indicated that the PIADS adequately captured their primary psychosocial concerns with continence devices, but had difficulty understanding some items, and the application of the response scale to other items.
A modified version of the PIADS for continence aids, which incorporates stigma assessment, will be pretested with samples of elderly device users and their caregivers to help assure that the questions and response formats are understandable and acceptable to the population of intended respondents. The internal consistency and test-retest reliability of the new instrument will then be examined. Finally, the validity of the new instrument will be examined in a study proposed for the NDA project, to evaluate two assistive devices (odour sensor and wetness sensing smart underwear) that have been requested by continence pad users themselves.

References


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