

TOWARDS ITEM DEVELOPMENT FOR THE PSYCHOSOCIAL IMPACT OF ASSISTIVE DEVICES SCALE FOR CONTINENCE (C-PIADS)

Hypothesis / aims of study

Continence difficulties (CD) can have a negative impact on psychological and social functioning; they have been associated with elevated levels of stress, feelings of powerlessness, isolation and depression. Assistive devices (ATD) are extensively used in continence management, from implanted devices to absorbent pads. Unrestricted and facilitated participation in human life is essential in the technology user's definition of quality of life outcomes (1), and it is therefore important to have valid, responsive and sensitive measures of psychosocial experiences associated with CD and its ATDs. Current outcome measures for continence ATDs do not adequately address psychosocial impact. Clinical assessment of treatment outcomes tend to focus on clinical issues and underestimate the degree of psychosocial impact perceived by patients (2) and although there are several validated instruments which are designed to assess the health-related quality of life, their validity for evaluating the effectiveness (especially the psychosocial impact) of assistive devices is unknown.

The purpose of this study was to explore whether the Psychosocial Impact of Assistive Devices Scale (PIADS), which has been shown to reliably predict the adoption and use of ATDs (3), requires modification to address the particular needs of continence ATD users, and to inform any subsequent item development. The provision of such a tool will enable patient-centred evaluation of new and existing technologies and facilitate the establishment of a robust evidence base on which to base treatment decisions for individuals with CD.

Study design, materials and methods

The study was conducted in Ottawa, Canada and Bristol, UK. It employed interpretive methods in which qualitative information from semi-structured interviews (10 to 30 minutes) was combined with the findings from cognitive interviews for questionnaire pre-testing. A purposive sampling strategy was used to recruit individuals who could provide information rich interviews. The objective was to provide opportunities for interviewees to spontaneously (i.e. without reference to PIADS) identify important concerns and issues that should be considered for developing a version of the PIADS for continence technologies. Face-to-face interviews were audio taped with permission from participants and transcribed. Recordings of the interview sessions were subjected to qualitative content analysis. Common themes were identified.

All participants at the Ottawa site and 20 of the 31 participants at the Bristol site were also asked to complete the PIADS while considering their currently used continence device by commenting on the suitability and appropriateness of PIADS for assessing quality of life outcomes resulting from their continence ATD and were encouraged to suggest supplemental items, (i.e. issues not represented in the PIADS).

Results

In Ottawa, 9 participants (M= 1; F= 8) were recruited with an average age of 80 years (63-86 years). In Bristol, 31 individuals, (M= 8; F= 23) were recruited with an average age of 56 years (17– 87 years). All interviewees self-reported CD and the use of ATDs to manage symptoms. All the participants at the Ottawa site used absorbent pads to manage their CD; at the Bristol site, 24 participants used pads (2 were in addition to other continence devices), 6 used intermittent catheters, 2 used Foley catheters and 1 had an artificial sphincter.

Semi-structured interviews: When prompted to describe their level of satisfaction with the technology, many participants indicated that they had no choice about their CD, and that the products were simply something that they "had to use". Some expressed dissatisfaction with their products, e.g. pads were not comfortable in hot weather. In the UK, the cost of products was frequently mentioned, with participants indicating that they were not eligible to receive 'free' (i.e. NHS funded) products. Several participants were not aware of alternative ATDs or treatment and were told that "it's a natural part of aging".

Restrictions to social and recreational activities were frequently cited as the reason for seeking help from clinicians. Participants used words like "assurance", "freedom" and "empowerment" in describing what they would like their ATDs to give them and do for them, and the need to strategize arose from an ever-present concern that one might have an accident and be embarrassed in public. Participants described how anxieties about others finding out about their CD, due to leakage, odour or visibility of device, led to restrictions in lifestyle, such as wearing black to disguise leakage. Some participants described a self-stigma, whereby the CD condition and its treatment had led to feelings of shame and a reduction in self-esteem.

PIADS: In general, participant narratives, as well as the subsequent themes and sub-themes arising from analyses corresponded well to the 26 items in the PIADS, and the three main PIADS dimensions of Competence, Adaptability and Self-esteem appeared to adequately cover the issues experienced by participants. Most participants appeared to be able to complete the PIADS without difficulty, although the design of the form caused problems for some and even with the assistance of the PIADS glossary, some items were queried, or felt that more than one interpretation may apply depending on the circumstances. A few were confused by the reverse rating of the items *confusion*, *embarrassment* and *frustration* (i.e. positive ratings denote negative psychosocial impact).

Several participants offered suggestions for new items for C-PIADS; one thought that 'feeling down' or 'depression' should be included, while another thought that 'optimism' was a better reflection of his state than *well-being*. Other participants suggested 'convenience' – around storage, portability and disposal of devices, and 'knowledge' – understanding of CD and performance of the device. Potential new items, derived from interviews with the Canadian cohort were indicative of the stigma felt by participants; these included *self-consciousness*, *fear of being 'outed'*, *social acceptance*, *secrecy*, *isolation*, *revealing to others*, *social participation* and *intimate relations*.

Interpretation of results

Expectations of device performance and device options were variable. There were no PIADS items that were judged to be inappropriate or irrelevant by more than a small proportion of the participants. The narratives indicated that the PIADS may be appropriate to assess quality of life effects attributable to CD intervention with some modification. Although several key *self-stigma* constructs are already present in the PIADS, these did not convey the degree of stigma associated with an activity (toileting) that is usually carried out (by adults) in private and the subsequent desire to conceal the condition and the device.

Concluding message

The PIADS appears to fundamentally address many, but not all, of the important psychosocial concerns of adults who have continence difficulties. A version for continence, the C-PIADS, will require modification of the PIADS and is likely to contain some new items. A better understanding of the stigma associated with CD and its ATDs will serve to inform modification.

References

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