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"A UNIQUE OPEN-ENDED PATIENT & CARER SELF-REPORTED INCONTINENCE TOOL: A PILOT STUDY"

Aims of Study
All established quality of life questionnaires use preset questions to evaluate the impact of incontinence on a patient. However these may not assist clinicians to identify and quantify the more troubling issues, which are more relevant to a treatment plan.
A simple, innovative goal-oriented clinical tool was developed for recording information about patients' and carers' priority issues and the degree to which they were affected by them – the "Self-Reported Incontinence Evaluation Tool" (SRIET). The tool was also used to assess the effect of the treatment strategies adopted in relation to those priorities.

Methods
The tool was developed with input from both clinicians and a patient focus group. It was then piloted over a 15 week period in both clinic and domiciliary settings, by either a continence nurse advisor or continence physiotherapist. A letter was sent to the patient/carer prior to the first visit, listing the types of problems/feelings people with incontinence commonly experience. It explained that their individual concerns/feelings would be discussed at the initial visit and they were encouraged to think about the ways incontinence was impacting on their lives.
The tool was completed at the initial visit and again at the time of discharge (completion group) or at the end of the study period (interim group).
Clients were able to list up to 5 of the ways in which they were most affected by their bladder/bowel problem and then these were self-rated for severity (priority) and frequency on a 0-4 rating scale (Figure 1).
Both clients and clinicians participated in a formal evaluation of the tool through individual interviews and non-parametric analysis was performed on the data collected.

Results
The tool was completed by 50 patients. The average age of the patients was 73.4 years (range 31-91years) with 78% female and 22% male participants. The average length of intervention was 12 weeks with an average of 4 contacts. The majority of clients found the tool acceptable providing they had adequate cognitive function. Clinicians????
The participants listed a total of 117 problems, which fell into 12 main categories. Most of the problems identified were of a psychosocial nature (74.1%) eg embarrassment/ loss of dignity. Other recurring problems were items such as loss of sleep/cost/concern about odour/hygiene/ social restriction etc.
A comparison of the two groups (completion versus interim) on their admission data, using a Mann-Whitney U test, revealed no significant difference on either the priority/severity ($p>.05$) or frequency ($p>.05$) of the problems identified.
Those who had completed treatment showed a significant improvement in both the priority ($p<.001$) and frequency ($p<.01$) ratings of their problems according to the Wilcoxon Signed Ranks test. Those who had not completed treatment (interim group) also demonstrated improvement in both ratings ($p<.001$) however their priority ratings were significantly higher than the completed group. (suggesting hat those who had completed treatment gained the most benefit, with some of the data being collected from the interim group early in their management programme).

Conclusions
The importance of patient/carer participation in defining their key issues was central to the development of the SRIET. Despite this being a pilot study, the SRIET has demonstrated its potential usefulness, not only as an outcome measure, but also more importantly as a measurable tool which can assist clinicians to prioritise their management strategies. With

further refinement and testing of the tool it should be possible to validate it against other "gold standard" outcome measures.

Figure 1

1. **What are the worst things about having / caring for someone with a bladder / bowel problem?**

Problem	Priority	Severity

2. **Priority Question:**
   How much does (…..) bother you? (Show rating card 1)

0	Not a problem
1	A small problem
2	A moderate problem
3	A large problem
4	Problem as bad as it could be

3. **Frequency Question:**
   How often does (…..) bother you? (Show rating card 2)

0	Never
1	Almost never
2	Sometimes
3	Fairly often
4	Very often