

QUALITY OF LIFE ISSUES FOR PATIENTS WITH SPINAL CORD INJURIES REQUIRING BLADDER MANAGEMENT DEVICES – THE PATIENTS' PERSPECTIVE.

Hypothesis / aims of study

The aim of this study was to explore the impact of bladder management on individuals with spinal cord injuries in order to inform the design of a self-completion quality of life questionnaire. Patient involvement in this process is imperative as advised by the Food and Drug administration, "patient reported outcome instrument item generation is incomplete without patient involvement" (1). Previous qualitative studies in this group of patients have explored general urinary dysfunction as opposed to management, which captures different aspects of impact on daily life (2). The development of such an instrument will enable a thorough evaluation of the patients' experience as described by them, for use in both clinical practice and future research.

Study design, materials and methods

Patients aged over 18 years with spinal cord injuries requiring active bladder management were invited from one regional spinal unit to participate in exploratory interviews to identify the key elements affecting quality of life with current bladder management. Audio-taped interviews using qualitative methods were undertaken in order to explore these issues in depth, as perceived by patients. Purposive sampling was employed to recruit participants who used three management devices: intermittent self-catheterisation (ISC), urinary sheath and supra-pubic catheterisation (SPC). The interviews were semi-structured employing a grounded theory approach with ongoing review of interview findings informing the focus of subsequent interviews until saturation was achieved and no new themes were identified. Audiotapes were transcribed verbatim, and a coding frame devised for analysis, according to emerging themes. Content analysis was conducted according to standard methods (3).

Results

Twenty five patients in total were interviewed in December 2006, (22 males, 3 females, mean age 48 years, range 23-72 years), incorporating ten individuals using ISC, nine individuals using SPC and six whose current bladder management took the form of a urinary sheath. Interviews ranged from 15 to 45 minutes in length.

The main theme identified was that of urinary leakage which was reported by fifteen of the individuals across all three management devices. This was qualified with the supplementary information that leakage was generally only a problem if the device was not being used as intended.

ISC users

"...a little bit might leak, that's if I haven't catheterised in time."

"...if I tend to hang on too long for any reason I can leak."

SPC users

"...if I'm doing something, say if I've been down the pub with the boys playing pool, then I can get a kink in my leg bag [causing a leakage]."

"...[leakage occurs] occasionally but it's mainly to do with if the line's kinked off and I ignore the, you know, the warning signs."

Urinary sheath user

"...just make sure that I empty my bag when it's gets full otherwise the urodome does blow up then."

Another major factor identified that minimised daily inconvenience, was preparation undertaken by individuals,

Equipment preparation

"I always carry a jar of clean water in the vehicle with me, I've got a catheter kept in the house at home in the toilet and I've got one that I carry in my car with me while we're travelling."

"I just put on a glove and then I don't have to worry about trying to get my hands clean in a public loo or anything like that."

"I could tell anybody how to do that [remove an SPC] I've always got the syringe in the bag and stuff so I'm always prepared."

"...and I have spare urodomes and a little towel and flannel."

Pre-emptive preparation

"...but if I'm out I try and make a point of going [voiding] before I go out."

"I make sure every time when I hop in the car I check to make sure that I'm not sitting on the tubing or things like that you know."

As touched upon within the issues of preparation, concerns regarding facilities in which to manage urinary devices were a prime concern, particularly in eight out of the ten individuals using ISC, as hygiene was also reported to be crucial to effective device management,

"There's been the odd occasion where I have been in a public toilet with no lighting or no water and stuff like that, but you tend to shy away from those sorts of situations if you can."

"I mean you've got to make sure that if you're going to use a public toilet it's got to be reasonably clean because you just can't dump your catheter on any old thing."

Issues such as access to facilities to be able to empty urinary collection bags were also a consideration in the participants using SPC and urinary sheaths, however, the option to be able to optimise outdoor opportunities were far more feasible in these groups.

Quality of the products supplied were a big issue for all users of urinary sheaths with 'blow-outs' due to substandard systems posing the main restrictions,

{describing a new cheaper sheath supply} ...these things you can hold up to the light and look through, they usually go ping and they crack and split and you have an accident... they're very fragile and it doesn't do your quality of life any good if you're down in confidence."

Interpretation of results

Urinary leakage caused by inappropriate use of all management devices was the main issue, suggesting that while this is a concern for those affected it is also largely within the individual's control. In much the same way preparation enables the majority of this group of patients to lead a reasonably unrestricted life with regard to their bladder management. Issues out of the control of these individuals are more likely to cause restrictions such as poor quality equipment and poor facilities, which were found to be predominantly a problem in those using urinary sheaths and ISC respectively. However, those who used ISC commented that it replicated 'normal' bladder function most accurately;

"...it's no different than the likes of yourself going to the toilet".

Concluding message

The qualitative interviews undertaken with this group of patients with spinal cord injuries using varied bladder management devices, has identified the most important issues that impact daily life when using these appliances. Importantly, it has highlighted that while there are common issues between the devices there are also individual issues that are more relevant with certain appliances. The identification of issues that are significant to patients and the impact on their daily life will enable the development of a more applicable, patient-centred quality of life measure.

References

1. <http://www.fda.gov/cber/gdlns/probl.pdf>
2. European Urology (2001) 39; 107-113
3. Research methods in health: investigating health in health services; Maidenhead, Open University Press, 2002

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