

ISC THE ROAD TO INDEPENDENCE: SPINAL INJURED PERSONS EXPERIENCES OF INTERMITTENT SELF CATHETERISATION

Hypothesis / aims of study

Bladder problems and incontinence are debilitating for people with spinal injuries often presenting the biggest challenges and negatively impacting on their quality of life. Intermittent self catheterisation (ISC) is the gold standard treatment option to manage bladder symptoms; however not all patients are accepting or compliant with it. There is little information on the patient experience. This study aims to explore the experiences of people with spinal injury to describe their experience of learning ISC, their perceptions of service provision in relation to ISC and the impact that it has on their life.

Study design, materials and methods

Qualitative methods were used, based on a grounded theory approach. Individual unstructured in-depth interviews were conducted in patient's homes. The interviews were audio-taped and transcribed. 15 people were sampled purposively to include both male (n=11) and female (n=4), with a range of ages (24- 68, median 52), and with varying spinal injuries. The data was analysed thematically with the aid of NUDIST software.

Results

All patients were taught ISC by the ward nurses on the spinal injury ward. Successful bladder management was considered crucial to maintaining a good quality of life. Most patients were positive about ISC, viewing it as the first step to independence, describing an aversion to indwelling catheters. They valued the nurses' expertise and good teaching /service provision whilst an inpatient. After discharge many patients viewed the aftercare in relation to bladder/ bowel care and support to be lacking and not meeting their needs. Many interesting themes emerged and are demonstrated in this table:

A Sample Of Common Themes	Example: Patient Quotes
ISC and Independence	"ISC was another step to independence, I just hoped to get some sort of independence, the consultant said because of the cerebral palsy I might not be able to do it ,so I looked at him and said "I'll have to find a way"
Importance of bladder /bowel management	"the only topic of conversation (in the ward) is bladder and bowel, because those are the two major things you pick up and learn about "
ISC fitting into lifestyle and providing symptom control	"watching the rugby...If I was going to have a few beers ,then there was a good chance of an accident ,whereas with ISC it doesn't happen at all and that's given me great confidence"
Complications UTIs	"if you are not a well person to start with it (UTI) can blow you away" "I had two major bouts of UTI ,they told me early on that the muscle is at risk of UTI"
The future :Concerns for the long term	"the only thing I do think of is when I get older, how will I manage then? Will I have an indwelling catheter when I am older?" "My concerns are long term, how does ISC affect things like sphincter muscle, the urethra?"
Lack of after care/support	"Once you have been taught in hospital and you leave, well there's no back up ,there's a cut off point when you leave hospital there's nothing after that and you are just left to get on with it"
Patients after care requirements /needs were not met	"If they came along and taught you a little more about hygiene... it would be nice if a professional would come in and say this is the correct methods of doing it (ISC). kept up to date on new products, ask you if you'd like to try them...would be a good idea"

Interpretation of results

The participants recruited to this study were mostly optimistic types with positive outlooks on life, which possibly influences compliance with ISC; this may not be representative of all spinal injured patients. One of the problems with this methodology is that it relies on the memory of individuals and their interpretation of events and information offered, which may be influenced by their emotional state and stresses encountered after the injury or event. This group still have a yearly appointment with the

spinal unit medical staff but a specialist review of bladder and bowel management regimes did not feature strongly, if at all in the discussion. Only one participant had been referred to a continence adviser for on-going support with ISC

Concluding messages

Incontinence is one of the major issues for spinal injured people and ISC allows them to manage this effectively, ultimately improving quality of life. Service provision around ISC is of a high standard in the acute rehabilitation period but patients would benefit from a referral to specialist continence advisers for the opportunity to discuss and review continence management. Clinicians involved in spinal injured patients need to consider the importance of after care and support needed for compliance and successful sustainability of ISC.

<i>Specify source of funding or grant</i>	Gwent Health Care R&D small grant scheme
<i>Is this a clinical trial?</i>	No
<i>What were the subjects in the study?</i>	HUMAN
<i>Was this study approved by an ethics committee?</i>	Yes
<i>Specify Name of Ethics Committee</i>	South East Wales ,Cardiff
<i>Was the Declaration of Helsinki followed?</i>	Yes
<i>Was informed consent obtained from the patients?</i>	Yes