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ATTITUDES OF WOMEN WITH MULTIPLE SCLEROSIS WHEN QUESTIONED ABOUT GENITAL TOUCHING AND CONTINENCE DEVICE PLACEMENT

Hypothesis / aims of study

People with multiple sclerosis (MS) are often advised to use intermittent self-catheterisation (ISC) but it has recently been shown that at three months following initial instruction 39% had either discontinued or had never mastered the technique(1). A study undertaken in 2000(2) suggested that many women with incontinence problems were disinclined to use continence devices because of taboos about genital touching. These authors developed and validated a linear analogue 10-item questionnaire which measured women's attitudes to becoming familiar with their genital anatomy and to placing devices into or upon the vagina or urethral orifices. They reported that only 15% of females (n=104; median age 60.5 years) attending an incontinence clinic were 'very comfortable' about placing an incontinence device on their urethra, and only 30% felt 'very comfortable' about touching the genital area. If these findings hold within the MS population it may account for some of the problems and reluctance associated with ISC within this population. This study aimed to identify if women with MS report similar issues relating to using urethral or vaginal devices and if this questionnaire has the potential to help clinicians identify which patients require additional support to master ISC.

Study design, materials and methods

Following ethical approval and obtaining permission from the author(2) the questionnaire was completed anonymously by female MS patients through local MS charities. The questionnaire itself was unmodified and included questions on attitudes and use of tampons, attitudes to looking and touching the perineal area, attitudes to using intraurethral and intravaginal continence devices, and knowledge of number and position of genital orifices. In addition we obtained demographic data which included age, length of time since MS diagnosis, use of mobility aids, presence of bladder problems, whether advised to use ISC, and if they were using ISC at present. Data were entered into SPSS V 16 statistical software package. Data analysis included use of descriptive statistics, and the chi square test of association.

Results

Sixty-six female patients with MS responded, median age 51 years (range 23-76). Median time since diagnosis of MS was 17 years (range 2-50) with 83% (55/66) stating they had bladder problems; 70% (46/66) had been advised to use ISC and 36% (23/66) were currently using ISC. There was a significant relationship between age and the reporting of bladder problems ($X^2 = 7.393$; df=5; p=0.024.), with older respondents (>50 years) more likely than younger respondents to report having a problem (88% vs 70%). The longer the person had MS the more likely they were to report having bladder problems ($X^2 = 33.198$; df=6, p=0.004) (duration of MS ≤ 20 years 79% vs >21 years 98%). Similarly, the more the person's mobility was impaired the greater the chances of reporting bladder problems ($X^2 = 12.208$; df=6; p=0.041) (walks unaided 49% vs wheel chair use all the time 100%). There was no significant relationship between age and present use of ISC. Overall around 30% were very comfortable (Score 7-10) with looking, touching or inserting a continence device into the urethra. As the table shows participants ≤ 50 years were more uncomfortable with the idea of inserting a continence device, but more comfortable about inserting a tampon when compared to those > 51 years

Question	How comfortable do you feel about placing a continence device or a catheter into the genital area (bladder opening)			How comfortable do you feel about touching the genital area?			How comfortable do you feel about inserting a tampon?		
Score Age (years)	% Very uncomfort-albe	% Moderately comfort-able	% Very comfort- able	% Very uncomfort- albe	% Moderately comfort- able	% Very comfort- able	% Very uncomfort- albe	% Moderately comfort- able	% Very comfort- able
≤50 (n=32)	77.4	6.6	15.8	58.8	18.7	22.2	25.4	24.6	50.0
>51 (n=34)	48.0	20.0	31.3	53.6	12.5	33.3	50.0	12.5	36.9
Total	57.8	15.6	26.6	52.2	18.5	29.2	35.8	18.9	45.3
Signifi- cance	X ² =15.443 df=10 p=0.030			X ² =9.208 df=10 p=0.256			X ² =9.983 df=8 p=0.088		

Table 1. Relationship between age and feelings of inserting a continence device, tampons and touching the genital area (n=66) Very uncomfortable 1-4; Moderately comfortable 5-6; Very comfortable 7-10

Only 37.5% (n=24) responded correctly to the number of genital openings but 68% located the urethra correctly on a diagram. Although there was a tendency for younger participants (≤50 years of age) to get these questions correct, these were not significant.

Interpretation of results

The successful use of ISC can transform the lives of many people with MS, but there are some who, apart from physical disability preventing them from undertaking the procedure, find it difficult to perform because of psychological and cultural problems. Over a quarter of participants in this study were very comfortable with the idea of inserting a continence device/catheter into the urethra, while in the original study(2) 15% were very comfortable. In the MS population this was age dependent with older women feeling significantly more comfortable with the idea than younger women; however the younger age group were relatively more comfortable

with using a tampon. Eleven participants were using ISC in the \leq 50 age group, and 12 in the >50 age group so the difference does not appear to be related to usage of ISC. Similar to the original study(2), only 29.2% in this study were comfortable with touching the genitalia. This was not significantly related to age although again, unlike the original study(2) there was a trend for older women to be more comfortable.

Concluding message

It appears from this study that patients of any age can feel very uncomfortable with touching or looking at their genitalia or inserting a catheter, and ability to use ISC is not age dependent. It may however be possible to use a questionnaire such as this to assess a patient's initial feelings of having to use a catheter so the clinician can determine who may need additional coaching.

References

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