Communication about sexual problems in male patients with multiple sclerosis


Abstract

Aim To explore the reasons given by a disability, assessment and rehabilitation team (DART) for perceived difficulties in discussing sexual problems with male patients with multiple sclerosis (MS), and to compare them with the views of a sample of patients.

Method Data were gathered from a multidisciplinary team who were responsible for assessment and rehabilitation of patients with MS, using a focus group and semi-structured interviews with 11 male patients. Data were analysed thematically, with reference to Annon’s (1976) model of communication.

Findings Patients felt a need to discuss problems with sexual dysfunction, and would welcome the introduction of the topic in a straightforward way. Health professionals were worried about intrusiveness and lack of information and training. Team members and the patients indicated that nurses are the best people to deal with these issues.

Conclusion Rehabilitation teams need training to deal with patients’ sexual problems, and the nurse is likely to be identified as the specialist in this area.

STIMATES IN the UK suggest that up to 70 per cent of men with multiple sclerosis (MS) have serious sexual problems, including chronic erectile dysfunction; and surveys in the United States suggest that the figure may be as high as 91 per cent (Sanders et al 2000). Research suggests that fewer than 20 per cent of men with sexual problems ever discuss them with health professionals (Rubin 2004). Sexual satisfaction is increasingly being considered a relevant variable in assessing social and family relationships (McCabe et al 1996) and in evaluating quality of life (Daker-White and Donovan 2002). These findings suggest that there are a high number of men with MS for whom quality of life may be impaired because of their inability to discuss their sexual problems.

Merritt (2001) suggests that ‘sexual dysfunction in patients with disabling physical or neurologic conditions is often overlooked by medical personnel, but it is a topic of great importance to both the patient and those with whom they share significant relationships’. There is an ongoing debate in many professions as to what extent sexual problems are valid concerns of particular groups of health professionals. In comparison with other health professions, the nursing and counselling literature encourages enabling patients to raise sexual concerns. Nevertheless, the situation is not yet regarded as ideal, and many voice their concerns. For example, Lewis and Bor (1994) state that when people suddenly become severely physically disabled, it is often implied that they must disregard their sexual nature. They write that while the nurse–patient relationship puts many nurses in an ideal position for providing information on sexuality to patients, this frequently does not happen.

Although sexuality should be incorporated in planning holistic nursing care for all patients, it is a subject that is avoided when healthcare professionals take patient histories (Borwell 1997).
It has been suggested by the medical profession that ‘patients often do not volunteer sexual problems and health professionals should inquire about sexual function. This is often met with relief rather than embarrassment’ (Penson et al 2000). Recent research on how GPs discuss sexual problems with older people concluded that, while patients wished the subject to be raised during the consultation, many GPs felt uncomfortable with this and felt unable to be proactive in talking about sex (Gott et al 2004). It is interesting therefore to examine how these barriers can be overcome.

A popular model for delineating the abilities needed when discussing sexuality is Annon’s (1976) Permission, Limited Information, Specific Suggestions, and Intensive Therapy (PLISSIT) communication system. The four progressive levels of the PLISSIT model require involvement based on the comfort level with this subject, knowledge base and counselling skills, and training of the healthcare professional. The PLISSIT model suggests that anyone in the health professions can provide some level of sexuality information for people with disabilities. It allows a broad range of service delivery, depending on the provider’s level of competence, and helps the provider determine the appropriate time for referral to another professional. Perhaps most importantly, it suggests ways of discussing sex. The levels of the model are shown in Box 1.

Although there have been recent developments in designing specific questionnaires to enable health professionals and patients to discuss sexual problems, notably the MS Intimacy and Sexuality Questionnaire-19 (MSISQ-19) (Sanders et al 2000), it is often unclear whose role it is to address the issues raised. Many patients with sexual dysfunction, especially men, will not raise the issue with health professionals and the latter may not necessarily raise the issue with patients.

Box 1. Four levels of the Permission, Limited Information, Specific Suggestions and Intensive Therapy model

- Permission – many problems can be ameliorated by giving permission to discuss sex. Health professionals who give permission need to be comfortable discussing intimate sexual problems
- Limited information – the health professional can offer the patient specific factual information directly related to his or her sexual concerns
- Specific suggestions – the health professional helps the patient to set and reach a specific goal to change behaviour
- Intensive therapy – this is generally considered to be the remit of specialised sex therapists, and referral is the desired outcome

(Anon 1976)

The aim of this study was to explore the reasons for any perceived difficulties in discussing sexual problems as perceived by a Disability, Assessment and Rehabilitation Team (DART) and male patients with MS. The purpose of this article is to contribute to the knowledge base of the views of multidisciplinary teams and patients regarding discussion of sexual problems.

Method

This was a qualitative study, with a cross-sectional design. A focus group was carried out with the DART team and semi-structured interviews with 11 male patients.

Ten members of a multidisciplinary DART, comprising nurses, occupational therapists, speech and language therapists and a physiotherapist participated in the focus group. They had been working with the same patient group for some time, using their own expertise as required, and their level of experience ranged from recently qualified to 20 years.

A semi-structured interview schedule was used during the focus group. It examined how team members thought they dealt with patients’ sexual problems. Prompts included questions on how they felt about dealing with sexual problems, and whose responsibility it should be to deal with sexual dysfunction among male patients with MS.

Eleven male patients who had responded to a letter requesting volunteers were recruited from the DART service. All had a diagnosis of MS. The number of years since diagnosis and age of participants were representative of the DART team’s caseload. A semi-structured approach was used for the patient interviews. Patients were asked about whether they wished to discuss sexual problems with health professionals, their past experience of this, what would enable them to discuss any sexual problems with health professionals and their preferences about receiving information. A tape recorder and telephone recording equipment were used for the focus group and the patient interviews.

Potential participants from the DART were approached by the researcher directly, with an information sheet requesting participation in a focus group on discussing problems in communication about sexual issues with patients diagnosed with MS. The group met for one hour. One researcher facilitated the discussion while the second researcher made field notes on the interactions between participants. The discussion was recorded with the permission of the participants and transcribed. Transcripts were sent to the participants and verified. Information letters were sent to all male patients of the DART, and those who replied that they were prepared to be interviewed were telephoned and asked whether they would prefer face-to-face or telephone interviews. Approximately half chose each method. Each interview lasted no more than 40 minutes because some participants had cognitive problems with concentration. Discussions focused on facilitating discussion of sexual problems between healthcare professional and patient. All conversations were tape recorded with permission, and the tapes were transcribed.

Permission to proceed with the study was given by the local research ethics committee. The ethics committee advised that participants should choose whether or not to be interviewed face-to-face. Letters of information were printed in large font to accommodate possible sight difficulties. The DART manager acted as consultant and trained the interviewer in ways to conduct the interviews without causing distress to the participants. The DART manager’s name and contact number were also sent to all participants for any advice they
might need given the sensitive nature of the questions. Confidentiality was ensured for the focus group by group agreement, and all tapes and transcripts were anonymised. The transcriber also signed a confidentiality agreement. All tapes were kept in locked filing cabinets and the computers satisfied data protection requirements. The tapes were destroyed after transcription.

Thematic analysis was undertaken. The first phase was deductive, using the categories from the PLISSIT model: giving permission, giving limited information and making specific suggestions. The second phase was inductive and involved allowing themes to emerge from the data, and fitting them into these three categories where appropriate. Relationships between the categories and themes were examined, taking into account the field notes from the focus group.

To maximise the reliability of the data analysis, two researchers independently identified themes and categories in the transcripts, coded the data and then identified examples of the themes verbatim. Discrepancies were discussed until there was agreement regarding the themes and examples. To maximise the validity of the data, major themes with examples were sent to the participants for comment. After some discussion with the DART about the use of the term ‘embarrassment’, the themes were agreed to be a fair representation of what was said.

Findings

The findings reported in this article are only those which are relevant to the first three themes of the PLISSIT model: giving permission, giving limited information and making specific suggestions. Subcategories are discussed within this framework.

Permission to talk about sexual problems

Much of the discussion among the DART participants centred on whether patients would want them to raise the issue of sexual problems:

‘Unless a patient alludes to it, it’s one of the first questions you shy away from because they’ll see it as being intrusive and if a patient doesn’t identify it as a problem, why should we go exploring it?’ (Participant A)

‘You can’t ask a leading question like “have you got any problems with sexuality?”’ (Participant E)

‘It’s only a problem if the patient sees it as a problem, surely… I think, unless they actually bring it up with you, then… should you actually go out trawling for that little problem?’ (Participant G)

One participant gave an example of experience:

‘Well I think several of us had examples where people told us to mind our own business, or… took the line of least resistance, or… we didn’t feel comfortable enough saying, making the request or stating the question… and if the patient wasn’t clearly… going to answer we didn’t pursue it in any shape or form.’ They also questioned whether patients needed to talk about sexual issues with them:

‘Is it something people need, that specific question?’ (Participant B)

Another DART participant raised the question of what to do if a patient said he or she had a problem, and the group discussed whether they would be embarrassed:

“We individually feel embarrassed, or agitated, or slightly vulnerable because our level of knowledge or our own emotional overlay is quite significant.’ (Participant A)

“I think the embarrassment would be in not having enough information.’ (Participant U)

“The actual discussion about it is not the problem, it’s the embarrassment of not being able to actually… [help]’ (Participant G)

However, one participant disagreed, suggesting that whatever the outcome, the patient needed to talk:

‘I think it’s equally valid that we just listen to the exposure of the problem then even if that doesn’t solve the problem, at least they have acknowledged it themselves and then from there you can actually move forward.’ (Participant D)

Sometimes, participants consolidated their views through the discussion. Here, they back one another up:

‘It takes an expert, you know, years and years and years or a psychologist years and years and years to get to know the things that these people are needing to know. We couldn’t possibly fill that gap, could we?’ (Participant H)

‘No.’ (Participant A)

‘Else only at the very most basic level.’ (Participant H)

‘And I don’t think we’d want to do that, because it’s a physical rehab team, so we want to help them.’ (Participant A)

‘Surely sexual function is a fairly physical…’ (Participant U)

‘It is!, but what I’m saying… would you like to spend hours and hours in dealing with that particular problem? No! He would like to have help, but your physio role and another area is a primary aim isn’t it?’ (Participant A)

‘Oh, sure… If any of us had wanted to do this specific therapy, we’d have gone off down that track. We would have gone to Relate and become a sex therapist. But I think, you know, we do shy away from [it].’ (Participant U)

When these comments are compared with those from patient interviews, there are some very different views. While acknowledging the potentially embarrassing nature of discussing sex, patients still wanted the health professionals to ask them about it:
 limited information

Participants from the DART expressed concern about not knowing what to tell patients, and some worried that they might give the wrong information. They also stated that it was unprofessional to put themselves in a position of encouraging patients to ask questions if they would not be able to answer:

"It's not that easy, it's not something we chaps like to talk about." (Participant 1)

"Sexual problem or activity has never been something that any doctor or physiotherapist or whoever has raised, they will raise things such as bladder difficulties... problems you're having in that way, but they won't, or in my case, they haven't really raised the aspect of sexual activity at all. Why that is I don't know." (Participant 2)

In particular, patients identified raising the topic as being problematic. This view is supported by the following comments:

"It's not something any of my doctors has ever raised in any way whatsoever." (Participant 3)

"It's getting going in the first place... the actual bringing up of the topic." (Participant 4)

"If it had come up I would have talked to them about it but it doesn't come up." (Participant 5)

"I think I could deal with it, it's just getting it started." (Participant 6)

"Ask the question straight. It's something you can't dilly dally around." (Participant 7)

One suggested:

"When you go straight in for an appointment, just say "do you want to talk about your sexual problems?"" (Participant 8)

Field notes suggest that some of the team members were embarrassed at discussing sexual issues. This was demonstrated by the considerable use of "um" when talking about the topics, much laughter and attempts to find euphemisms for sexual behaviour. At no point in the focus group discussion were any sexual acts or parts of the body named by any participant. There was no suggestion from the interviewer that any of the patients were embarrassed by the topic.

Limited information

Participants from the DART expressed concern about not knowing what to tell patients, and some worried that they might not know what to do if he did not feel that he was going to do if
We need to know a named person first.’ (Participant A)

‘I think the nurse [general murmurs of agreement].’ (Participant C)

Patients also agreed that the nurse is most appropriate to deal with sexual concerns:

‘If you have got something like MS, the nurse or someone like that are there for that sort of thing. It would be a lot easier to talk to them about it. Rather than say your local GP…’ (Participant 1)

Some had a different idea, suggesting referral to a specific sex therapist:

‘A sex therapist… yeah, that might be handy. Because they probably know what they’re talking about.’ (Participant 3)

These examples demonstrate potential conflict between the patient’s desire to talk to the nurse, who is perceived as the easiest to confide in, and the desire to receive information from whoever is most knowledgeable. Ideally, this should be the same person, but it can be seen from the excerpts that this is not felt by the DART participants to be the case.

Limitations

This was a small study, with just one multidisciplinary team and a small sample of patients, which makes it challenging to apply the findings to other areas. Currently, there are no other published studies with which to make a comparison. More studies need to be carried out to see if the findings are widespread or a consequence of lack of training in dealing with sexual problems in this particular health authority.

Any qualitative analysis, even with high inter-rater reliability, is open to interpretation. It would be necessary to use triangulation with observations of the interactions between health professionals and patients to verify what actually takes place, although ethically this might present problems.

It is possible that the focus group method was a factor in the content of the discussion. It was apparent throughout that the group, who worked together, were consistently working to maintain harmony. Therefore, potential disagreements may not have been expressed by individuals. This problem would have been resolved by individual interviews. However, on a day-to-day basis, the group make decisions of this kind by talking to one another, and therefore it could be argued that the focus group is the best representation of their usual decision-making process.

Discussion

The findings demonstrated that the patients perceived a need to talk about their sexual problems, preferring a situation where they expected to be asked direct questions, possibly in their own homes. The health professionals, however, were worried that patients would not like to be asked about sexual problems and may see such questions as intrusive. In Annon’s (1976) terms, the health professionals were wary of giving permission to talk about sex, while the patients wanted this permission. It was clear from the interviews that patients were unlikely to raise the subject, but when the subject was mentioned by a health professional, they were happy to discuss it. This accords with the findings of Benson et al. (2000) and Merritt (2001). There was unanimous agreement that the patients wanted to talk about some aspect of sexual dysfunction. The team members were worried that they did not have enough information to give patients, and this was embarrassing. Patients, however, were divided over this. Some expressed the wish to receive immediate information, but others were content to be referred to an expert. Sex therapists and nurses were mentioned specifically, with many suggesting that it would be easier to talk to a woman. This was interesting because a considerable part of the team’s discussion focused on deciding who would be the best person to refer the patients to, and the nurse was the most popular named professional. The best possible solution for health professional teams and patients would seem to be a home visit from a female nurse, who is trained to give limited information to patients with sexual dysfunction and knows who to refer patients to for more guidance.

Concern about expression of sexual problems is not confined to MS, to men, or to the UK. An American study outlined the problems that lack of discussion of sexual dysfunction brought to renal dialysis and transplant patients (Hart et al. 1995). The authors recommended using the PUSSIIT model to aid health professionals to communicate in this area. The model is also recommended to aid nurses in discussion of sexual problems with patients after an ostomy (Sprunk and Alteneder 2000). Ovarian cancer is another area where the model might be useful. In a recent study, female patients with this diagnosis were interviewed about their communication with health professionals (Stead et al. 2001). The women said that they had not been asked about sexual issues. As in the current study, the participants wished that they had been asked, although they accepted that they might have found the topic difficult.

Conclusion

Although this was a small study, an unmet need for enabling patients with disabilities to discuss sexual problems has been identified. These limited findings need to be acknowledged by interdisciplinary teams, to request appropriate training for nurses which will enable them to fulfil this crucial role.

Implications for practice

- There is a need for patients with disabilities to be enabled to discuss sexual problems
- Nurses are the most appropriate professionals within the multidisciplinary team to undertake this role
- There is a need for more specific training and education so that nurses can address patients’ concerns in an effective and open manner

REFERENCES


