Sexuality and Disability, Vol. 23, No. 4, Winter 2005 (© 2005)
DOI: 10.1007/s11195-005-8929-9

Sexuality in Stroke Care: A Neglected Quality of Life Issue in Stroke Rehabilitation? A Pilot Study

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Although there is a substantial body of literature on the physical and psychosexual consequences of stroke, there is a paucity of empirical studies on the experiences of rehabilitation professionals in addressing sexuality issues with patients during the rehabilitation process. This is the first small-scale pilot study in Northern Ireland, informed by a comprehensive literature review, which explores the experiences of health and social care professionals in addressing sexuality issues with patients and their perceptions of the training they require in this area of stroke rehabilitation. Questionnaire survey data were collected from community and hospital based stroke professionals in a Health and Social Services Trust in Northern Ireland. The study groups comprised nurses, doctors, physiotherapists, occupational therapists, speech and language therapists and social workers. The findings revealed that although the majority of staff had been asked for advice on sexuality issues during rehabilitation, most of them had received no training in this aspect of stroke rehabilitation since joining stroke services. The findings suggest that all rehabilitation professionals need to become more knowledgeable about sexuality issues in stroke care and could benefit from further education and training in comprehensive sexual health care.

KEY WORDS: stroke rehabilitation; sexuality; interdisciplinary; education and training; Northern Ireland.

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INTRODUCTION

Stroke is a common cause of death and disability. It is estimated that about 10,000 strokes a year occur in people under retirement age in the United Kingdom (UK) with as many as 300,000 living with disabilities caused by a stroke (1). While the effects of stroke can be relatively minor and temporary, survivors with more severe, long-term disabilities such as paralysis, speech and language difficulties and sensory lapses are likely to require inputs from rehabilitation professionals in the acute and possibly post-acute phases of the rehabilitation process (2). As the needs of patients following a stroke are often multiple and complex, a co-ordinated, inter-disciplinary team approach to rehabilitation has been shown to reduce mortality as well as contributing to improved functional outcomes for stroke in-patients (3,4). However, according to Forster and Young (5) the criteria used in determining positive outcomes for stroke patients have tended to focus on 'functional ability' which has led to an increasing neglect of the emotional and social consequences of stroke. While the goals of minimising the functional effects of stroke and maximising patient autonomy in stroke rehabilitation are clearly important (6), an area often neglected by professionals is the effects of stroke on sexuality and the sexual health of stroke survivors.

The paper begins with a review of literature which examines the psychosexual effects of stroke on patients and some of the challenges involved for rehabilitation professionals in addressing sexuality issues with survivors post-stroke. It then draws on a small pilot questionnaire survey that explored the experiences of rehabilitation staff in this area of practice and briefly discusses some of the key findings. To conclude, the paper highlights a number of policy and training implications that could be considered by stroke care providers to improve the service and points to the need for further research in this field of rehabilitation practice.

Literature Review

Research findings from studies throughout the 1980s (7–9) and 1990s (10–12) have highlighted the negative effects of stroke on sexual function, personal relationships and quality of life. For example, Boldrini et al. (10) in a study of 86 patients found a marked decline in sexual activity in both genders, post-stroke. Similar findings were reported by Korpelainen et al. (12) in a 6-month follow-up study of 50 stroke patients in Finland. The research found that in addition to a marked decline in sexual activity among those surveyed, 28% of respondents at 2 months post-stroke and 14% at 6 months had ceased having sexual intercourse. An earlier study by

Monga et al. (13) reported that decreased libido and diminished frequency of intercourse were experienced by both male and female survivors of stroke, while in other studies (14,15) impotence and erectile difficulties were identified as particular problems for post-stroke men. Other research studies (16) found that the effects of stroke can delay the initiation of sexual activity and create relationship difficulties in the post-discharge period, as each partner waits for the other to initiate sex. In a recent study by Korpelainen et al. (17) involving 192 stroke patients and 94 spouses, a marked decline was reported in respondents' libido, coital frequency, erectile and orgasmic ability and vaginal lubrication, as well as dissatisfaction with sexual life in the post-stroke period. The research found that an inability to discuss sexuality and an unwillingness to participate in sexual activity were key explanatory factors for these changes, lending support to earlier findings (e.g., Buzzelli et al. (18) that psychological rather than physical factors account for the disruption of sexual functioning in stroke survivors.

As a result of the increasing awareness of the negative psycho-sexual effects of physical disability and chronic illness on patients, there is a growing recognition among interdisciplinary professionals of the importance of counselling and support during the rehabilitation process (19). A number of studies have emphasised how sexual functioning and intimacy can be affected by cancer (20,21), stoma surgery (22) and spinal cord injury (23,24) and have highlighted the importance of education and counselling during the treatment and rehabilitation phases. The onset of stroke, as with other chronic conditions, has not only a major physical impact on survivors (2), but can also have profound social, cognitive, and psychosocial effects on the patient's quality of life and rehabilitation potential (25–27).

An area often overlooked by stroke care professionals in the assessment and rehabilitation process is patients returning to their normal sexual activity (28). Johnstone (29) states: '... it is important for the patient to understand, as he gets better and resumes normal living, that there is no reason why he should not resume a former normal [married] relationship... There is no medical reasoning for abandoning a former way of life' (p. 7). Although it has been shown (30) that patients with disabilities are clearly interested in having the issue of sexuality included in their rehabilitation and accord it a high priority, there is evidence to indicate that rehabilitation professionals frequently ignore the discussion of sexual issues with stroke survivors (31). Research by Waterhouse (32) and Gutherie (33) has shown that nurses for example tend not to routinely address issues of sexuality unless the patient asks specific questions. Clifford (34) has suggested that in nursing 'the subject of sexuality often remains an area of limbo' and is seen by nurses as 'the work of experts, as

long as the expert is not me' (p. 360). Results from other studies (35,36) have confirmed that while health professionals agree that patients' sexual issues need to be addressed, they do not feel comfortable discussing them. Research by Mc Cormick et al. (37) on coital positioning for couples post-stroke found that no one had spoken to the wives of stroke survivors about sexuality issues at any time throughout the rehabilitation period. Other research (38) has shown however that aphasic patients and their spouses are open to discussing sexuality with a physician and have specific medical, physical and psychological issues they want to address.

Although it is clear that patients would welcome sexuality issues being routinely incorporated into the rehabilitation process, the evidence suggests that it may be health care professionals who are more inhibited about discussing sexual issues with patients due to embarrassment, a lack of training or other related factors. In a study by Kelleher and Oxenham (39), embarrassment was found to be a contributory factor in deterring nurses from discussing topics such as sexuality with patients. Similarly, Kautz et al. (40) reported that the discussion of such issues was avoided by nursing staff for fear of causing unnecessary patient distress and anxiety or because they believed the patient did not wish to discuss sexuality issues as part of their rehabilitation programme. While there would appear to be a consensus among stroke rehabilitation staff that professional advice is needed for stroke patients and their partners (28), what is less clear is the extent to which stroke professionals feel sufficiently comfortable and skilled in addressing sexuality issues with patients during rehabilitation. Despite the growing research evidence on the psychosexual difficulties that patients can experience following a stroke, there is a paucity of empirical studies on the extent to which discussion of sexuality issues features in stroke rehabilitationists' practice and how comfortable they feel in addressing this sensitive area with stroke survivors.

The aim of the present pilot study was to explore the experience of hospital and community based rehabilitation professionals in addressing sexuality issues with patients and to determine how comfortable they felt about this component of professional practice. The research also sought to identify respondents' perceptions of future training needs in this area of stroke care.

METHODS

The views of a total population sample of 7 members of a local community based stroke team and a convenience sample of 10 members of the hospital stroke team in the same locality were elicited using a self-administered questionnaire. Eligibility for inclusion in the study was therefore

restricted to staff who were members of either a multi-disciplinary hospital or community rehabilitation team and who were employed in stroke services. Due to the exploratory focus of the research and the sensitive nature of the topic, a questionnaire was considered to be the most appropriate instrument was as it could be completed anonymously and would possibly encourage respondents to be more frank in their responses (41). Prior to conducting the research, permission was sought from the relevant authorities within the participating Health and Social Services Trust. First, the aims and objectives of the study were discussed informally with the manager responsible for stroke services. This was then followed with a letter confirming the purpose of the study and the methodology to be employed. Following authorisation to undertake the study, a letter explaining the purpose of the survey and the questionnaire were sent to the 17 hospital and community based stroke professionals, via the stroke services manager, inviting them to participate in the study. Two weeks were allowed for the return of the questionnaires in the stamp addressed envelop.

The 20-item questionnaire, which was developed specifically for the study, comprised four sections. Demographic data, such as age, gender, professional designation was elicited first. The second section sought details from respondents about their level of experience in addressing sexuality issues with patients before working in stroke services as well as training undertaken in this area of practice ("Before working within stroke services had you any experience of addressing sexuality issues with patients?... If yes, please give details"). The third and most extensive section focused on respondents' experiences of patients seeking advice on sexuality issues within current practice and their comfort in responding to these requests ("Has a patient ever asked you for advice regarding a sexual issue?... If yes, how comfortable were you in addressing this issue?"). Respondents were also asked about the amount of training they had received in addressing sexuality issues with patients since joining stroke services; and some of the reasons why they may have difficulty engaging patients on this topic. Section four aimed to identify respondents' attitudes towards addressing sexuality issues in their future practice and the knowledge and skills required to enable them to work effectively with patients in this sensitive area of professional practice ("What knowledge and skills do you think are necessary to enable you to discuss sexual issues with patients?" and "How strongly do you agree that training on sexuality issues should be provided for professionals in stroke services?"). The questionnaire incorporated a combination of open-ended and closed questions as well as Likert-type questions. A small number of questions requiring ranked responses were also used. The final part of section four invited respondents to add any other comments they wished to make on the topic. A total of 13 questionnaires were returned by the 2-week deadline,

representing a 76% response rate. A content analysis was carried out on the data collected and common themes were recorded. Relevant qualitative statements from respondents were used to illustrate the findings.

FINDINGS

Demographics

All of the respondents were women whose ages ranged from 30 to 49 years. The professional designations of the overall sample included: 4 nurses, 3 occupational therapists, 2 physiotherapists, 2 speech and language therapists and 2 social workers. Hospital based respondents had worked in stroke care for an average of 6.6 years (range 3.5–15 years) while community based respondents had on average been employed in stroke services for 4.8 years (range 3.5–11.5 years). Two of the hospital based professionals and one member of staff from the community team had worked in stroke services for over 10 years.

Experience of Addressing Sexuality Issues Before Working in Stroke Services

Respondents were asked about their experience in addressing sexuality issues before working in stroke services. Ten out of the 13 respondents had no experience of addressing sexuality issues with patients in their previous work settings. Three professionals, all nursing staff, reported they had 'some experience in this area'. One hospital nurse had discussed sexuality issues within 'generic care of the elderly' while another hospital based nurse reported she had 'occasionally discussed sexuality issues with patients in relation to heart disease/drug side effects' in a general medical ward. Just over half of the respondents across both settings stated they had anticipated that addressing sexuality issues with patients would be part of their professional role. However 12 out of the 13 had received no training in this area before joining stroke services.

Involvement and Comfort in Addressing Sexuality Issues in Current Practice

Respondents were asked about the extent to which sexuality issues had arisen in their present practice and how they had responded. Nine professionals across the hospital and community settings had been asked

by a patient on at least one occasion for advice on an issue of a sexual nature and only four respondents had never been asked for advice on this aspect of stroke rehabilitation. In relation to respondents' level of comfort about addressing this type of issue, most of those surveyed reported they would generally 'refer' the patient to an agency with more expertise in this area, such as the local Northern Ireland Chest, Heart and Stroke Association, if they felt uncomfortable addressing a sexual matter. A smaller proportion indicated they would 'seek the advice of the multi-disciplinary team'. One community based professional commented: 'I think I'd probably go ahead but feel embarrassed'.

When asked to rank, in order of importance, the main reasons why they might have difficulty addressing sexuality issues with patients from a list of seven reasons (lack of experience; own personal beliefs; fear of offending the patient; lack of training; other professionals' responsibility; embarrassment; and 'other reasons'), 11 out of the 13 respondents identified lack of training as the main reason. A similar proportion cited lack of experience as the second main barrier to discussing sexual matters with patients post-stroke while over half felt they would be inhibited through embarrassment and fear of offending the patient.

Respondents were uncertain as to whether procedures for addressing sexuality issues existed in both the hospital and community based settings. Five respondents across both settings thought protocols existed whereas eight were of the opinion that no procedures are currently available. The routine response of staff in both settings is to provide patients with the Stroke Association leaflet *Sex after stroke illness* (42) and, if appropriate, have an 'informal chat' with them. One community based respondent commented: '... patients have requested written information on this issue in the past and there was very little available'.

The views of whose responsibility it should be for addressing sexuality issues with patients were equivocal. Some hospital based professionals felt that the responsibility should lie with a nurse or doctor while others suggested that the social worker would be the most appropriate professional to deal with these types of issues. A hospital based social worker stated: '... discussion of sexuality should be part of the social work role in helping the patient regain quality of life'. While a minority of the rehabilitation staff thought the patient's general practitioner or a nurse would be the most appropriate professionals to undertake this role, most felt that the matter required an interdisciplinary response which drew on each professional's area of skill and expertise. One community based respondent commented: 'This is not the specific remit of only one professional group. All of the team should be equipped to at least feel comfortable to enable the patient to discuss their problems'. Such an approach, it was believed,

would allow the patient to discuss the issue with the person with whom they felt most comfortable.

Interestingly, since joining stroke services none of the hospital based staff and only two members of the community stroke team had received 'some training' of an unspecified nature on addressing sexuality issues in stroke rehabilitation. However 11 out of the 13 respondents had not received any training on this aspect of rehabilitation. Whereas over half of those surveyed considered that this had affected their ability to discuss these types of issues with patients, a minority of respondents felt unaffected by lack of training as they had never been approached for advice or help in this aspect of stroke rehabilitation.

Views on Future Training Needs on Stroke and Sexuality

Respondents were asked about their future training needs in relation to sexuality in stroke care and the knowledge and skills that would be necessary to enable them to discuss these types of issues with patients. Most of them suggested that future training should include a variety of topics including: the impact of stroke and its psychosocial implications; body image and identity following stroke; effective referral procedures in stroke services; communication and interpersonal skills in stroke care; and psychosexual counselling skills in stroke rehabilitation. The majority agreed that training in counselling and interpersonal skills would help to further develop their ability to empathise with patient needs and to respond with a greater level of sensitivity and insight. Eleven of the rehabilitation professionals 'agreed' or 'strongly agreed' that training on sexuality issues should be provided to all staff working in stroke services. One respondent commented: 'The sooner all professionals recognise the need for appropriate training in this area, the better'. There was a strong consensus among the respondents that future education and training on sexuality issues in stroke care should be workshop based and be facilitated by a qualified, independent psychosexual trainer.

DISCUSSION

As the results indicate, a high proportion of those surveyed had many years experience working in stroke care and possessed considerable knowledge of interdisciplinary working in this specialist area of healthcare. The majority of respondents however had no previous experience in addressing issues relating to sexuality before working in stroke services which may indicate the low priority given to issues of sexuality and

disability at organisational and structural levels of professional education and training (43). On the other hand, it is possible that staff may not have been required in their previous posts to routinely enquire about patients' sexual health issues or have considered sexuality as a central aspect of the patient's quality of life (44–46). A focus on the physical or 'functional' aspects of patient care may therefore have taken precedence at the expense of a more holistic assessment of the patient's situation.

Despite the constraints imposed by ageing and ill-health, it should not be assumed that the meaning and significance of sexuality in the lives of older adults necessarily declines (47). The study's finding that many of the respondents had been asked for advice on sexuality issues by stroke patients clearly lends support to this argument. In addition, it challenges the stereotypical and discriminatory view held by many that older, disabled people do not have intimate relationships or are, at worst, asexual (48,49). Results reported here by a large majority of respondents that lack of training and experience would inhibit their ability to address sexuality issues with patients post-stroke, confirm the findings of earlier studies (40,50). In a more recent study (51), poor knowledge, skills and training were identified as some of the main barriers that affected general practitioners' (GPs) ability to effectively address sexual dysfunction issues with their patients. Taken together, these findings add to an emerging picture which suggests that while health and rehabilitation professionals are regularly required to address sexual health issues with patients in their daily practice, a lack of appropriate education and training in this area can affect their ability to respond to these issues in a comfortable and skilled way.

Professionals involved in counselling disabled patients who have sexual difficulties are not required to be trained psychosexual counsellors. They do however need to be aware of psychosexual issues in patient care and to feel comfortable in creating the therapeutic space in which issues and concerns can be sensitively explored (52,53). As most of the respondents from both settings in the present study had not received any training on sexuality issues since joining the stroke services, a number of policy and training implications seem apposite for stroke care providers to consider.

Policy and Training Considerations

The findings of the study suggest that rehabilitation professionals could benefit from on-going, in-service training opportunities to develop their knowledge, comfort and skills in sexuality counselling to enable them to offer a more responsive and sensitive service to stroke survivors during the rehabilitation process. There is a need at strategic and organisational

levels for policy makers and service providers to see sexual rehabilitation following a stroke as an integral part of sexual health care in later life. In addition, sexual rehabilitation following a stroke also needs to be recognised as an important quality of life issue for older people and clear protocols developed to guide and assist staff in this area of practice. The absence of policies and procedures relating to sexual rehabilitation in the present study would seem to reflect a wider national picture in the UK for example of the low priority given to sex and sexual health issues in later life. Indeed the paucity of published work on sexuality-related issues in stroke rehabilitation more generally may even suggest that this quality of life dimension of stroke care has been of less interest to the stroke rehabilitation research community. As noted by Gott and Hinchliff (47), the lack of reference to sex or sexual health in two recent Department of Health directives in the United Kingdom *The National Services Framework (NSF) for Older People* (54) and the *National Sexual Health Strategy* (55) may implicitly reinforce the ageist stereotypes held by many in society that sex and sexuality are unimportant for older people, despite research evidence to the contrary (56).

It could be argued that the dearth of adequate training materials to develop the sexual counselling skills of rehabilitation staff and provide them with the knowledge, comfort and skills necessary to undertake their work more effectively may be one reason why sexuality training in stroke care has been so neglected over the years. However an interdisciplinary education and training programme on comprehensive sexual health care in spinal cord injury rehabilitation, developed by Mitchell Tepper (57), may offer a useful template for stroke care providers to guide and inform the development of a training curriculum for rehabilitation professionals. The adaptation of such a model, which is underpinned by a policy of continuing education and training for staff in human sexuality, should provide appropriate opportunities for each member of the rehabilitation team to develop the requisite skills and knowledge to comfortably address any sexual questions or concerns that patients may have. Creatively designed education and training programmes, incorporating sensitive facilitation methods, have been shown to help reduce anxieties in medical undergraduates about sexuality and improve confidence in skills development in this field of patient care (58). Rehabilitation professionals should be equipped, at minimum, to sensitively and informatively respond to any sexual questions patients may have and, if necessary, direct those with more complex needs, for example patients with aphasia, to specialist forms of help (38).

The time is now right for sexual health issues in stroke care to be accorded a higher priority on the policy agendas of health service providers and recognised as a fundamental quality of life issue for stroke survivors. Although the implementation of any new training initiative may

present both professional and managerial challenges towards improving the quality of interdisciplinary teamwork in this area of stroke rehabilitation, Kilbury et al. (59) suggest that once changes in policy and practice are introduced, shifts in attitude and behaviour are likely to follow.

Study Limitations

The present study is the first survey in Northern Ireland and, it would appear, within the UK to explore the experience of hospital and community based stroke rehabilitation professionals in addressing sexual issues with patients and their level of comfort in responding to this component of practice. The study however has several limitations. The sample size was small and localised and it is therefore difficult to generalise the findings to other populations of stroke professionals. In addition, as all of the respondents were women, the views of male stroke rehabilitation professionals were not reported in the study. It is also possible that respondents may have had differing interpretations of 'sexuality issues', as no definition was prescribed. Finally, the use of a questionnaire for data collection afforded respondents only a limited opportunity to express their views on the issues being explored. Despite these shortcomings, the diversity of the sample in terms of the participation of health and social care professionals offers important insights into the experience and attitudes of rehabilitation professionals to discussing sexuality issues with stroke survivors in one Health and Social Services Trust in Northern Ireland. The results of the study also allow for a tentative degree of hypothesising about the extent to which the issues identified by staff in this research study may be similar to those experienced by stroke rehabilitation professionals in other parts of the UK and elsewhere.

Future Directions

Due to the exploratory nature of the present small-scale study, the authors clearly acknowledge that the findings are only able to provide preliminary insights into this sensitive area of stroke rehabilitation. More positively, it is hoped that the dissemination of our findings will provide the impetus for further research in this neglected dimension of rehabilitation. The pilot study reported here makes a small, but informed, contribution to this under-researched sphere of stroke care. Given the dearth of empirical studies on the topic, there is clearly a need for further qualitative research to be undertaken in a range of acute care, community and rehabilitation settings, using larger and more representative samples, to provide

more detailed data in this field. Research into the effectiveness of training programmes in comprehensive sexual health care implemented for rehabilitation staff in the future will also be important so that the positive gains in knowledge, comfort and skills development for course participants can be measured and other relevant research questions identified.

CONCLUSION

Our study has shown that while stroke survivors have particular sexual health needs during the rehabilitation process, the majority of health and social care professionals surveyed had received no training in this area of stroke care. If the sexual health needs of stroke survivors are to be addressed in a sensitive and holistic way, then rehabilitation professionals need to be afforded opportunities to develop the appropriate skills and knowledge in this area of professional practice. It is suggested here that the strategic and coordinated implementation of ongoing in-service training in comprehensive sexual health care for all members of interdisciplinary stroke teams could make a significant contribution to the development of a more patient-centred and responsive service. It is also possible that such a strategy may better equip interdisciplinary team members to work in a more empowering way with stroke survivors in this important, but neglected, field of stroke rehabilitation.

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