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ALEXANDRA F. RICHARDS BSc Hons

SEXUALITY WITHIN STROKE REHABILITATION

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Doctor of Clinical Psychology

SEPTEMBER 2014

SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY

SEXUALITY POST-STROKE AND WITHIN REHABILITATION: A REVIEW OF THE CURRENT
RESEARCH FINDINGS AND LITERATURE

DECLARATION FOR MAJOR RESEARCH PROJECT

Candidate name Alexandra Richards
(PRINTED)

DECLARATION

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed A.Richards.....
(candidate)

Date 15/04/2014.....

STATEMENT 1

This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

Signed A.Richards.....
(candidate)

Date 15/04/2014.....

Signed *Muel H Burger* (supervisor)

Date 15/04/2014.....

STATEMENT 2

I hereby give consent for my thesis, if accepted, to be made available to external internet users through the CCCU institutional repository and the British Library EThOS service, and for the title and abstract to be made available to outside organisations.

Signed A.Richards.....
(candidate)

Date 26/09/14.....

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Summary of MRP

Section A is a broad review of the literature relating to post-stroke sexuality and how this has been addressed to date within stroke rehabilitation. Initially a contextual overview is given followed by a review of the literature concerning the impact of a stroke on sexuality. Following this the literature relating to how sexuality has been approached within stroke rehabilitation and available interventions are reviewed. The review concludes with recommendations for future research.

Section B presents a grounded theory of the process by which healthcare professionals within stroke rehabilitation engage with the sexual concerns of their patients. A conceptual model is outlined. Ten healthcare professionals (HCPs) working within stroke rehabilitation were interviewed. The differing ways in which HCPs engage with patients in relation to sexual issues is presented. A process is suggested by which HCPs personal level of comfort around sexuality interacts with a series of personal, societal and organisation barriers to limit the action they choose to take. The findings are presented in relation to existing evidence and policy, and the implications for clinical interventions for patients and staff are discussed, alongside directions for future research.

Section C contains the appendices of the first two sections.

MAJOR RESEARCH PROJECT

ALEXANDRA F. RICHARDS

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Abstract

This paper reviews the literature on the impact of stroke on sexuality and how sexuality has been addressed within stroke rehabilitation. An overview of the current context of stroke, rehabilitation and the concept of sexuality is first given. This is followed by a broad review and critique of the research findings of the last ten years on the sexual consequences of stroke. This is discussed in terms of sexual functioning and also psychological and social aspects of sexuality. The relationship between common post-stroke impairments and sexual difficulties is discussed, and the current evidence of causes of post-stroke sexual difficulties. Post-stroke sexual difficulties have repeatedly been found to be common, but the use of narrow definitions of sexuality and limited samples has limited understanding in the area. The review then addresses the role sexuality has taken to date within stroke rehabilitation. Limited research has been carried out but evidence suggests the topic is often neglected. Finally, directions for future research are discussed.

Key words: Stroke, Sexuality, Sexual Functioning, Rehabilitation

Sexuality Post-Stroke and Within Rehabilitation

The impact of a stroke on sexuality and sexual functioning has been increasingly recognised and studied over the past 30 years. More recently researchers and clinicians have begun to consider the role of sexuality within stroke rehabilitation, and to consider how stroke survivors might best be supported in relation to this. The primary focus of this review is to examine the literature on the impact of a stroke on sexuality and how this has been addressed by healthcare professionals within stroke rehabilitation. An overview of stroke and the current context of stroke rehabilitation are provided, before introducing a current understanding of the term “sexuality” and its contribution to quality of life. Subsequently, the literature on the impact of stroke on sexuality, and the literature on how the topic of sexuality has been approached within stroke rehabilitation is considered and reviewed systematically. Suggestions for future research are given.

Contextual Overview

Stroke

The term “stroke” is used to refer to brain damage caused when blood flow to the brain is disrupted. It is a serious medical concern, estimated to be the UK’s third largest cause of death and the largest single cause of disability (National Stroke Strategy, 2007). Common consequences of a stroke include paralysis on one side of the body (hemiplegia), difficulty in communication (aphasia) and cognitive difficulties. These difficulties may be long-lasting, and an estimated half of stroke survivors are dependent on others for everyday activities (National Audit Office, 2010).

Stroke Rehabilitation

Stroke care and rehabilitation has developed significantly over the last decade. Following recommendations from the National Stroke Strategy (2007), public awareness campaigns were developed with the aim of increasing public knowledge of stroke and its' warning signs (Bray, O'Connell, Gilligan, Livingston & Bladin, 2010). A key message of these campaigns is that stroke is a medical emergency and medical attention as soon as possible after symptoms appear is essential. Early hospital admission may reduce the potential negative consequences of a stroke. The development of thrombolysis treatment (Hacke et al., 2008) has also increased the proportion of individuals who survive a stroke. However, increasing age is a risk factor for stroke and there is likely to be an increase in stroke presentation as the proportion of the population at advanced age increases (National Audit Office, 2010). Around three quarters of individuals who have a stroke will survive, but they may be left with difficulties that severely limit their independence and quality of life. Rehabilitation is therefore essential to aid stroke survivors to increase their level of functioning. Rehabilitation is defined as *"a process aimed at enabling them (people) to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination."* (World Health Organisation, 2013, p. 1). It is a holistic process incorporating the needs of the individual, and usually involves multidisciplinary team input. Variation exists between stroke teams, but they often involve input from nursing, medicine, physiotherapy, occupational therapy and speech and language therapy. Stroke rehabilitation begins in hospital, and depending on individual need, will continue in the community when the stroke survivor is well enough to be discharged from hospital. Advances in medical treatment and increased provision for neuro-

rehabilitation in the community has meant that now more individuals are fit to leave hospital earlier, and may continue their rehabilitation at home through support from Early Supported Discharge teams (National Stroke Strategy, 2007) and community stroke rehabilitation services.

Sexuality

Sexuality is a broad term that covers far more than just the activity of sexual intercourse. Whilst encompassing observable sexual behaviours and physical responses, sexuality is also a psychological concept that makes up an important part of an individual's sense of self and interpersonal relationships. The World Health Organisation (2006) offers the following definition: *"Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviour, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors."*(p.5).

Since researchers began to study sexuality in a scientific manner in the 1960s, various models have been developed of human sexuality. Earlier models (such as Masters and Johnson's Sexual Response Cycle, 1966) focused on stages of physiological response: excitement, plateau, orgasm and resolution. These models have been criticised for neglecting psychological factors but set a foundation for the categorisation for sexual disorders/dysfunctions (e.g. Masters & Johnson, 1970), which are seen as a difficulty experienced at any stage of the cycle.

A more holistic model that conceptualises sexuality in a broader sense, including psychological aspects, was developed by Woods (1987). It includes three components that are interconnected: sexual function, sexual relationships and sexual self-concept. “Sexual functioning” would involve the aspects previously described in the models of sexual response. “Sexual self-concept” here refers to the individual’s image of themselves as a man or woman and their perceived adequacy in masculine or feminine roles. A similarly psychologically-focused model is also described by Dailey (1984) who defined sexuality through five aspects: sensuality (awareness and acceptance of the body), intimacy (need and ability to experience emotional closeness), sexual identity (discovering who you are in terms of sexuality), reproduction (fertility, conception and caring for children) and sexualisation (use of sexuality to influence and control others).

The different definitions researchers have adopted have impacted on how they have studied sexuality, and the findings they have generated. Individuals may also have their own view of what sexuality means to them, and how they wish to express it. Sexuality has been recognised as an important part of life and ability to express sexuality in the way one chooses and to experience good sexual health are indicators of a good quality of life (Chadwick, Saver, Biller & Carr, 1998). Sexuality has been recognised as an integral part of general well-being and also an important aspect of healthcare, as indicated in key documents such as the UK Department of Health’s White Paper: Healthy Lives, Health People (2010).

Literature Review of Impact of Stroke on Sexuality and its Role in Rehabilitation

This broad literature review focuses on research on post-stroke sexuality published between 2003–2013 to reflect the most recent knowledge and also to reflect modern

developments in attitudes towards sexuality and also advances in stroke care. A review of the literature prior to 2003 can be found in Thompson and Walker (2011), Kautz, Van Horn & Moore (2009), Monga & Osterman (1995) and Burgener & Logan (1989).

Search Strategy

The review utilised a broad definition of sexuality, as used by the WHO and draws on papers that refers to the psychological as well as the physical aspects of sexuality. Papers which focused on “sexual functioning” (as defined medically) and the presence of “sexual dysfunction” were included as well as papers that utilised a broader definition. See Appendix A and B for search methodology and summary of included papers.

Structure of Review

In part one the evidence on the general prevalence of sexual consequences and on commonly reported changes is summarised. In part two, correlates of post-stroke sexual difficulties and evidence for physical and psychosocial causes are reviewed. Then, in part three, the available literature on approaches to sexuality within stroke rehabilitation is considered.

Measures of Sexuality

Research into post-stroke sexuality is shaped by the ways in which researchers choose to define sexuality and to collect and measure data. The terms “sexuality” and “sexual functioning” can be defined in many different ways and different cultural groups may differ in how they understand these terms.

Quantitative studies have tended to use questionnaire methods and standardised scales to quantify sexual changes. Often this requires the participant to rate themselves on a series of sexuality-related variables, often indicating a pre-stroke rating for comparison. Dysfunction has been labelled in relation to significantly different pre- and post-stroke

ratings, or use of a standardised measure of dysfunction. Two classic studies of post-stroke sexuality developed their own questionnaire (Monga, Lawson & Inglis, 1986, adapted by Korpelainen, Nieminen & Myllylä, 1999), which measures sexual functioning using ratings on seven different measures: frequency of sexual activity, sexual satisfaction, libido, erection, ejaculation, vaginal lubrication and orgasm. This questionnaire has been adapted and used in more recent research (e.g. Akinpelu, Oose, Odele & Odunaiya, 2013; Tamam, Tamam, Akil, Yasan & Tamam, 2008). Other measures used included the International Index of Erectile Function (Rosen et al., 1997) and Hudson's Index of Sexual Satisfaction (1998).

Unless studies are carried out prospectively, data on pre-stroke sexual functioning may be limited by memory, which is frequently impacted, post-stroke (Stroke Association, 2012). Communication difficulties and lower levels of literacy may also limit participants' ability to complete questionnaire measures.

Questionnaire methods may require the researcher to impose their definition of sexuality on the participant, rather than exploring what the term means to the individual. If the researcher and their participants do not share a view on what sexuality is, the data may not adequately represent the participants' experiences and neglect significant aspects. Qualitative studies have usually adopted a broad definition of sexuality and enabled participants to adopt their own definition that is relevant to their experiences.

The topic of sexuality is often seen as a sensitive topic. This may impact on data collection as participants may feel uncomfortable and be inhibited regarding the sharing of information. The wish to be viewed in a socially desirable way may also restrict the information participants share with researchers. These factors may potentially be limited by using questionnaire measures, which may provide a more comfortable method for participants to be open about experiences.

Physical aspects of sexuality may be more readily operationalised than the psychological (e.g. quantifying degrees of desire and satisfaction). However as these physical measures are usually collected from self-report rather than direct measurement (with the exception of Korpelainen, Kauhanen, Kemola, Malinen and Myllylä's 1998 study) they may still be subject to inaccuracy and bias in reporting.

Prevalence of Sexual Consequences After Stroke

Research and recognition of how a stroke might impact on sexuality has grown over the past decades, although there is evidence of interest in this area as early as 1961 (Kalliomaki, Markkanen & Mustonen). Several reviews of the literature over the previous decades (Burgener & Logan, 1989; Calabria, Gervasi & Bramanti, 2011; Kautz, Van Horn & Moore, 2009; Monga & Osterman, 1996; Thompson & Walker, 2011) have all concluded that difficulties relating to sexuality are common after a stroke. However, as similar difficulties continue to be reported today as they were in the 1980s, there appears to have been little progress made in overcoming the barriers to resuming sexual life.

Research into post-stroke sexuality has found a high prevalence of sexual changes across a diverse range of countries, despite the potential for very different sexual attitudes and beliefs between these cultures. In a study involving Nigerian stroke survivors attending a physiotherapy clinic, Akinpelu et al. (2013) found that 94.8% of the participants reported dysfunction in at least one of seven sexual areas (libido, coital frequency, vaginal lubrication, erection, ejaculation, orgasm and satisfaction with sexual life). Similar findings have been found in stroke survivors in Turkey (Tamam et al., 2008) and Korea (Jung et al., 2008). The measures used in research have tended to focus on western perspectives on sexuality and have rarely been adapted for different cultural views. The meaning stroke survivors give to sexual issues may vary considerably and this is not reflected in the findings.

Frequently Observed Sexual Changes Following Stroke

Frequency of sexual activity. An often-reported consequence of a stroke is decline in frequency of sexual activity, with some stroke survivors ceasing activity completely. In a study interviewing 103 Turkish stroke survivors with mild or no disability, Tamam et al. (2008) compared pre- and post-stroke functioning. Significant decreases in sexual activity were experienced by both genders. When discussing the topic of “physical contact” and “physical intimacy” with stroke survivors, Thompson and Ryan (2009) found that most participants reported a reduction in sexual activity and were reluctant to engage in activities such as kissing and cuddling. In a study of 62 Italian stroke survivors, Giaquinto, Buzzelli, Di Francesco and Nolfo (2003) reported 50% of participants had no sexual activity one year post-stroke. A decline was also found in male Korean stroke survivors (Jung et al., 2008).

Decline in frequency has often been assessed using questionnaire measures of pre- and post-stroke levels of activity. Some studies have however applied a norm for frequency of sexual activity. In Akinpelu et al.’s study (2013) they defined “coital frequency dysfunction” as coitus occurring twice a month or less, though this frequency may not have been problematic for all participants. If researchers impose their own definitions of “normal” sexual activity that do not reflect participants’ experience, then data collected may not be a valid representation of participant experiences. In many studies “sexual activity” refers to frequency of sexual intercourse rather than other sexual activities. An exception is Kim and Kim (2008), who used a more inclusive measure that includes independent sexual activity and sexual activities other than sexual intercourse (the Sexual Frequency Scale, McCabe & Taleporos, 2003). Questionnaire measures of frequency may leave little room for individuals to use their own definition of “sexual activity”, which may not focus on penetrative intercourse.

Arousal and excitation. Arousal and excitation are considered to be stages of the sexual response cycle (Masters & Johnson, 1966). Commonly investigated aspects include the ability to gain an erection and ejaculation in men, and vaginal lubrication and ability to orgasm in women. Information on these aspects has usually been collected from self-report (often questionnaires) and decreases in functioning are usually reported on all measures.

Tamam et al. (2008) and Akinpelu et al. (2013) both found declines on all measures of arousal and excitation. In a study of 605 male stroke survivors in Qatar, 48.3% were found to have erectile dysfunction (Bener, Al-Hamaq, Kamran & Al-Ansari, 2008), and similar results were also found by Paraskevas et al. (2008) in Greece. Comparing 109 male stroke survivors with age-matched controls, Jung et al. (2008) found that the patient group experienced significantly decreased erectile functioning post-stroke.

Libido. “Libido” refers to sexual desire (Oxford Dictionaries, 2013) and is a psychological component of sexuality. Research into sexuality following stroke has often asked participants to rate their level of libido, and a decline has frequently been found. The prevalence of decline in libido following stroke is estimated at between 17% and 42% (Calabro, Gervasis & Bramanti, 2011). When Thompson and Ryan (2009) interviewed 16 stroke survivors they found that 15 had reduced or complete lack of sexual desire post-stroke. Less common is “hypersexuality”, in which individuals experience an increase in libido and desire for sex, which may not be matched by their partner (Rees, Fowler & Maas, 2007). A very small minority of participants have reported increased sexual activity, which in some cases is described as uninhibited and “deviant” (Gianquanto et al., 2003).

Sexual Satisfaction. Satisfaction is another psychological component of sexuality and refers to the fulfilment of a desire and the pleasure associated with this (Oxford Dictionaries, 2013). “Sexual satisfaction” is not an objective term and individuals may create

their own definition and meaning (Pascoal, Narciso & Pereira, 2013), which may limit the ability of researchers to accurately measure sexual satisfaction using questionnaire measures. Decline in satisfaction from sexual activity has frequently been found following stroke (Boosman, Schepers, Post & Visser-Meily, 2011; Giaquinto et al., 2003; Tamam et al., 2008).

In Akinpelu et al.'s (2013) study of Nigerian stroke survivors, only 40% of participants reported dissatisfaction with their sexual life, despite the high prevalence of "sexual dysfunction" in this sample. They related this to their population's cultural views on relating sexual satisfaction to the ability to have children. Jung et al. (2008) also found that 76% of their sample (the majority were experiencing significant sexual changes) were satisfied with their current sexual life. Chambon (2011) also found that eight out of 16 of their participants (who had hemiplegia) had a "satisfactory sex life". These studies highlight the importance of taking into account the cultural context of participants and the meanings they give to sexuality. Kautz, Van Horn and Moore (2009) comment that a measure of "satisfaction" may need to be interpreted alongside measures of sexual frequency as different individuals may be satisfied with different frequencies of activity and this may also vary between members of a couple.

Self-image. Many studies have found evidence that following a stroke, survivors may experience changes in how they view themselves, their body-image and self-esteem. There has been some overlap with Woods (1987) concept of "sexual self-concept", with individuals feeling unable to carry out roles they previously held, including those associated with their sense of masculinity/femininity. Participants have reported lack of confidence and feeling unattractive. This may cause individuals to lack the confidence to initiate sexual activity or to see themselves as changed and now undeserving of a sexual life. Self-image may be a

difficult concept to measure and has often not been included in quantitative studies, arising more often in semi-structured interviews.

Thompson and Ryan (2009) found that stroke survivors viewed themselves as significantly changed after stroke. Participants described feeling self-conscious due to their changed appearance, which made them reluctant to engage in sexual activity. In a study which explored the experiences of being a stroke survivor (Murray & Harrison, 2004), participants spoke about a “loss of self” and difficulties reconciling their sense of self and identity with their changed bodies. Participants had lost confidence and male participants described feeling emasculated by their disability. Unusual for research in this area, the majority of their sample was unmarried. These participants raised concerns about their ability to form and maintain a romantic or sexual relationship and viewed their disability as making them undesirable to potential partners.

Stroke survivors’ feelings of being unattractive to others may in some cases reflect an unfortunate reality. In a study of 62 stroke survivors and their partners (Giaquinto et al., 2003), 88.7% of partners were unwilling to engage in sexual intercourse with the stroke survivor. Partners described experiencing a lack of sexual attraction to the stroke survivor, with some even expressing feelings of horror.

Impact on Partner and Relationship

Research studies that have focused broadly on the experiences of stroke survivors and their partners post-stroke have noted that participants often report changes in their romantic and sexual relationship (Banks & Pearson, 2004; Murray & Harrison, 2004). Research has sought to include the perspective of partners and has found that decline in sexual functioning occurs in both the partner as well as the survivor (Schmitz & Finkelstein, 2010). In a longitudinal study of the psychosocial functioning of the spouses of stroke

survivors, 67% of participants were dissatisfied with their sexual life at one year post-stroke, increasing to 72% at three years (Visser-Meily, Post, van de Port, Forstberg-Warleby & Lingeman, 2009).

A stroke may cause major changes to a couple's relationship (Schmitz & Finkelstein, 2010). The stroke survivors involved in Thompson and Ryan's (2009) study reported significant relationship changes, including changes in roles (particularly gendered roles) and changes in relationship dynamics. This was particularly the case when a partner took on a "carer" role, which was been experienced by some participants as incompatible with sexual and romantic roles (Schmitz & Finkelstein, 2010). Many participants in Thompson and Ryan's (2009) study described feeling unable to express any physical intimacy to their partner and viewing them more as a "best friend" than a lover. Those that still engaged in sexual activity reported feeling an obligation to their partner and not experiencing pleasure. If stroke-survivors are not physically able or do not desire to engage in sexual activity, this may mean that spouses effectively "lose" their sexual partner, potentially leading to sexual dissatisfaction. However, research has suggested that partners' reactions to the stroke-survivor may also limit ability to resume a sexual relationship. Giaquinto et al. (2003) described the concept of the "turned-off partner" as a key finding in their study of sexual functioning in stroke survivors and their partners a year post-stroke. Social desirability may however limit how able partners feel to express to researchers their reduction in desire for the stroke-survivor.

Relation to Other Consequences of Stroke

Researchers have investigated the correlates of sexual dysfunction within the stroke population to gain understanding of possible causes and contributors to these difficulties. Many of the consequences of a stroke have the potential to indirectly impact on sexuality

(Cheung, 2008; Rees et al., 2007). Hemiplegia may limit the body positions and movements that are possible during sex. Perceptual neglect and loss of sensation may alter the sexual experience and fatigue and pain may limit ability to engage in sex. A stroke may cause drooling, incontinence and emotional lability, which may be seen as unattractive and may impact on the stroke survivor's body image and self-confidence. Cognitive impairments may impact negatively on a couple's sexual life and change how a partner views the stroke survivor (Banks & Pearson, 2004). Many stroke survivors may have pre-existing health conditions (such as vascular disorders and diabetes) that may also cause sexual problems. Many medications used to treat consequences of a stroke and co-morbid conditions can also impact on sexual functioning (Calabro, Gervasi & Bramanti, 2011). However, the relationship between post-stroke impairments and sexual difficulties is not clear-cut, as difficulties are not universal to all experiencing these consequences (e.g. Chambon, 2011).

Co-morbid conditions and factors. Many risk factors for stroke have also been found to impact on sexuality and be associated with declines in sexual functioning. There is a greater risk of stroke and other chronic health conditions with increasing age, and sexual functioning has also been found to decline with age (Ginsberg, Pomerantz & Kramer-Feeley, 2005). Use of measures of pre- and post-stroke sexual functioning suggests that stroke survivors often experience dysfunction beyond what would be expected given their age (e.g. Giaquinto et al., 2003). Increased weight, diabetes and cardiovascular disorders are also associated with impaired sexual functioning (Kautz, 2007). Bener et al. (2008) found risk of post-stroke erectile dysfunction increased with age, obesity, presence of hypercholesterolemia, diabetes and hypertension and use of associated medications.

Communication difficulties. Many stroke survivors will experience changes in their ability to communicate following their stroke. An estimated third of the stroke population

experience aphasia (Lemieux, Cohen-Schneider & Holzapfel, 2001), which can include difficulties in expressive and receptive language. These difficulties may place restrictions on sexuality in many ways, including limiting the stroke-survivor's ability to initiate sexual activity and communicate their sexual desires and needs to their partner. Due to the difficulty involved in interviewing individuals with aphasia, their views are often absent from the literature. To date only one pilot study has explicitly looked at the impact of post-stroke aphasia, and it has yet to be repeated (Lemieux, Cohen-Schneider & Holzapfel, 2001). Their study suggested that a decline in sexual functioning was experienced that was similar to that reported in non-aphasic populations. However, the results also suggested that sexual changes may be experienced in different ways by individuals with aphasia. In contrast to other studies, some of the couples reported an increase in sexual activities other than intercourse, such as caressing and kissing. Spouses reported that their partners' reduced ability to express feelings or engage in intimate conversations was a great loss to their relationship.

Mood. Depression is common after stroke (Kim & Kim, 2008) and anxiety, apathy and emotional lability are also observed in some individuals. These mood difficulties sometimes appear to be related to the location of a stroke, and in others appear to be a reaction to the experience of having a stroke and its consequences (Stroke Association, 2012). Stroke survivors who experience depression appear to be more likely to have sexual issues post-stroke. Akinpelu et al. (2013) found depression had a significant impact of post-stroke sexual functioning and depressed individuals were more likely to experience sexual dissatisfaction and erectile dysfunction. In a multiple regression analysis, Kim and Kim (2008) also found frequency of sexual activity had a negative relationship to level of depression. However the presence of depression has often been an exclusion criterion in

studies of post-stroke sexuality, which limits the possibility of further exploring the relationship between post-stroke depression and sexual issues.

The nature of the relationship between post-stroke depression and sexuality is not clear, as sexual dysfunction is a common symptom of depression (American Psychiatric Association, 2013), but depression may also be reactive in relation to loss of sexual functioning (Rees et al., 2007). Individuals who are more functionally impaired post-stroke may also be more likely to experience depression and sexual dysfunction (Giaquinto et al., 2003), which may relate to their experience of developing disability.

Potential Causes of Sexual Problems Following Stroke

What do stroke survivors and their partners think are the causes? There has been limited consensus on the exact cause of sexual difficulties following a stroke, but some researchers have asked stroke survivors and their partners what sense they make of their experiences and what they attribute them to. How individuals understand their own sexual difficulties may be as significant as the actual cause, as their own attribution may influence how they cope with the difficulty, if they seek support and how it impacts on their view of themselves (Rotter, 1954). In Thompson and Ryan's (2009) study participants related their sexual difficulties to medication and fear of having another stroke. In other studies participants have also explained their difficulties in terms of medication (Banks & Pearson, 2004) and the presence of physical changes (Schmitz & Finkelstein, 2010). Participants appear more likely to attribute their difficulties to physical causes rather than psychological factors. This may reflect a medical focus in their treatment (Thompson & Ryan, 2009) and a predominantly medical view of sexuality. Viewing sexuality from this perspective might encourage seeing the difficulty as a "dysfunction" beyond individual control that must be treated by an "expert". Medical treatment for erectile dysfunction (such as use of Sildenafil)

has become increasingly widespread and is considered as evidence that stigma around sexual difficulties has decreased (Tepper, 2000). However this may reflect a preference of both professionals and patients to think of sexual difficulties in terms of a medical model, rather than considering the contribution of psychological and social issues.

Psychosocial contributors. The lack of a clear relationship between location of stroke, stroke severity and level of disability with post-stroke sexual difficulties (e.g. Giaquinto et al., 2003; Tamam et al., 2008), suggests that physical factors cannot fully explain the sexual difficulties experiences by stroke-survivors. Research has explored the role of psychological and social factors in the experience of sexuality post-stroke.

A factor particular to the stroke population is the fear that sex will cause another stroke. Fear of recurrent stroke has frequently been found in both stroke survivors and their partners (e.g. Giaquinto et al., 2003; Tamam et al., 2008). Many stroke survivors believe that sexual activity could dangerously increase blood pressure, and therefore abstain (Thompson & Ryan, 2009). Evidence however suggests that risk of a stroke brought on by sexual activity is very low (National Clinical Guidelines for Stroke, 2012).

The sexuality of individuals with disabilities is often stigmatised or ignored (Tepper, 2000). Individuals may have internalised these negative societal attitudes, leading them to believe that their impairments make them unattractive and precludes them from expressing their sexuality. Some questionnaire-based studies have enquired into individuals views and commonly found negative views about sex and disability and the view that a sex life is only for those who are healthy (Giaquinto et al., 2003). These views have been found in both stroke survivors and their partners.

The level of importance an individual attaches to sex has been found to relate to degree of sexual functioning. Those who hold sex as more important may be more

distressed by post-stroke changes in sexual functioning, although they could also be more motivated to find different ways of expressing sexuality post-stroke. The importance attached to sex may differ between genders, ages and cultures and be dependent on the definition of sexuality used in the research. For example: in Tamam et al.'s (2008) study, only 10% of female participants viewed sexuality as important, compared to 84.1% of the men. However in Schmitz and Finkelstein's study (2010) the majority of their participants (stroke survivors and their partners) expressed a strong need for emotional and physical intimacy.

Difficulty communicating about sexual issues with a partner has been repeatedly reported in stroke-survivors and is associated with greater sexual difficulties (Akinpelu et al., 2013; Thompson & Ryan, 2009). In Schmitz and Finkelstein's study (2010) both stroke survivors and partners described discomfort speaking about sexual matters, with some referring to feelings of shame or modesty. If individuals struggle to speak about sexuality, this may limit their ability to discuss the issues with their partner and also professionals, which could potentially be helpful and generate some ways of coping.. This is reflected in the literature, where response rates to questionnaires and requests to be interviewed are often low and some participants declined due to the sensitive nature of the research (Duits, Van Oirschot, Van Oostenbrugge, & Van Lankveld, 2009; Thompson & Ryan, 2009).

Reviews on the area of post-stroke sexual difficulties have frequently concluded that sexual difficulties following stroke are rarely due to the consequences of the stroke alone (Rees et al., 2007), with some reviews concluding that psychosocial factors play a greater role (Kautz et al., 2009; Thompson & Walker, 2011). The exact mechanisms for how these psychosocial factors impact on sexuality is as yet unclear, but it appears that a stroke has the potential to have a great impact on an individual's sense of self and self-esteem, as well

as their relationship with their partner. These changes may be less easily identified than the physical consequences of stroke, and may be more apparent later on in rehabilitation.

Whilst some sexual issues appear to relate directly to physical impairments, many sexual difficulties may be a secondary consequence of the changes in identity, self-esteem and relationships that may follow a stroke.

Limitations of Research

Participant Characteristics

The majority of research into stroke survivors' experiences of sexuality has focused on a younger group (e.g. Thompson & Ryan, 2009) with low levels of disability and exclusion criteria often include chronic health conditions, cognitive impairments, aphasia and depression. Older stroke survivors are frequently excluded from these studies as they are more likely to have a chronic health condition and to have cognitive and sensory impairments, and they are less likely to have a sexual partner (Ginsberg, Pomerantz & Kramer-Feeley, 2005). Whilst these exclusions may reduce bias as many of these factors have been suggested to impact negatively on sexuality, the resultant participant groups may not truly be representative of the stroke population as a whole. Excluded individuals may experience even greater difficulties relating to sexuality, or they may respond differently to post-stroke changes.

Research may not reflect the diversity of sexual identities and practices. Participants have tended to be heterosexual married couples who engaged in regular sexual intercourse pre-stroke. This excludes the perspectives of individuals who are single, non-heterosexual or engage in other "less traditional" forms of relationship or sexual activity, such as individuals engaging in casual sex or those paying for sex. There may be an underlying assumption in

researchers that sexuality is only of relevance to those in relationships (particularly those who are married). Given that stroke is more common in women (Stroke Association, 2013), men have been over-represented in the research. There has been a suggestion that sexual difficulties are more frequently reported by men (Kim & Kim, 2008), though this may reflect a sampling bias or a greater willingness of men to speak about sexual issues.

Definitions of Sexuality

Some research studies have adopted a rather narrow definition of sexuality and sexual dysfunction, focusing on physiological aspects of sexual intercourse. This can carry assumptions of what “normal” sexual activity should be, marginalising the perspectives of individuals who may experience their sexuality in ways other than through sexual intercourse.. Researchers have often used different methods of measuring the presence of problems relating to sexuality and sexual dysfunction, some developing their own questionnaires or adapting measures. Given the variety of definitions of sexuality and measures used, it is possible that these studies are not investigating entirely the same phenomena and it is not valid to compare them as such. Very different results may be collected in studies where sexual functioning is assessed by comparing a series of measures of pre- and post-stroke ability (e.g. Giaquinto et al., 2003) compared to qualitative interview studies where participants are encouraged to adopt their own definition of sexuality.

Breadth of Study

The majority of the literature on post-stroke sexuality has been quantitative and predominantly collected measures on physical aspects of sexuality. This may relate to these aspects more readily lending themselves to measurement, as opposed to the psychosocial aspects of sexuality. This quantitative data on prevalence of different sexual issues has highlighted an area of need. However it does not tell us what these difficulties mean to

individuals and how they experience them. This information may be crucial in terms of considering how to support individuals. The literature has suggested that post-stroke sexual issues are impacted by other consequences of the stroke and also pre-morbid factors. Studies that have explored sexuality within the context of overall adjustment following a stroke (e.g. Banks & Pearson, 2004) have begun to investigate the how sexuality relates to the other changes experienced by stroke survivors, and future research may benefit from a similarly broad focus.

Detection of “Dysfunction”

In exploration of post-stroke sexual dysfunction, few studies mention the degree of sexual dysfunction found in the “normal” population. Shah (2009) reported that 40-45% of women and 20-30% of men were thought to have at least one sexual dysfunction. In one study of post-stroke sexual functioning 50% of the female participants experienced sexual dysfunction prior to stroke (Cheung, 2002). Only one study included in this review used a control group (matched by age, Jung et al., 2008). Post-stroke sexual dysfunction needs to be viewed with consideration with the high level of dysfunction already occurring in the population.

Researchers have commented on “surprising” results in which, despite evidence of “sexual dysfunction” on given measures, participants actually reported satisfying sexual lives (Akinpelu et al., 2013) and did not desire professional input (Jung et al., 2008). This may suggest a short-coming of quantitative measures of sexual functioning that cannot tell us how an individual interprets a given change and what it means to them. If an individual does not view a sexual change as problematic then it may not be meaningful to think of it in terms of “dysfunction”. Qualitative studies and measures drawing on more holistic models

of sexuality (e.g. Woods, 1987) may give a more meaningful account of stroke survivor's experiences of sexuality.

Lack of Attention to "Functioning" Individuals

None of the studies reviewed found sexual difficulties in the entirety of their sample, yet little attention has been given to individuals who do not experience sexual difficulties following stroke. Infrequent incidences of increased sexual activity or desire in participants were referred to in terms of "hypersexuality" (e.g. Giaquinto et al., 2003) and there was little reference of an increase in sexual activity that might not be viewed as problematic. As such, the research to date has revealed little on what factors might enable a stroke survivor to cope and manage sexually.

Time-Scale for Data Collection

Research has varied in terms of how soon after a stroke data was collected from participants. For example, Thompson and Ryan's (2009) sample included participants from two months to four years post-stroke. At an early stage participants might not be fully aware of the consequences of the stroke and they may not have resumed sexual activity. Giaquinto et al. (2003) found that if participants resumed activity, this occurred between three and six months post-stroke. Later inclusion has the risk of participants forgetting information about their pre-stroke sexual functioning. Many studies have not given a rationale for the time point at which they collected data.

Cultural Variation

Research into post-stroke sexuality has taken place in a wide range of countries, but to date little emphasis has been placed on different cultural understandings of sexuality and how this might relate to the experience of post-stroke sexual changes. Participants have tended to have been recruited from hospitals and rehabilitation facilities, which means that

the views of stroke survivors who use non-western medical approaches (which may be common in some countries, e.g. South Korea, Choi-Kwon, Lee, Park, Kwon, Ahn & Kim, 2005) are not included in the research.

Sexuality Within Stroke Rehabilitation

Despite an acknowledgment that sexuality is an important part of life, it is often neglected within the rehabilitation process. Measures of rehabilitation outcome (e.g. Functional Independence Measure, Stineman et al., 1996, Barthel Index, Collin, Wade, Davies & Horne, 1988) often do not cover sexuality, so problems relating to sex may remain unnoticed. To date very little research has been published on how the area of sexuality has been approached within stroke rehabilitation. The available material is reviewed as preliminary guidance on how sexuality could be addressed.

Sexuality Within Stroke Policy

The importance of considering sex and intimacy following stroke has been highlighted in national policies and guidelines relating to stroke care. In the National Stroke Strategy (Department of Health, 2007) “sex and relationships” is set out as a key component of stroke rehabilitation. It recommends that individuals who have had a stroke and their carers receive training in “management of sex and relationships” along the stroke care pathway. The Royal College of Physicians’ National Clinical Guidelines for Stroke (2012) also highlights the inclusion of support for sexual dysfunction within stroke rehabilitation. This document recognises the importance of sexual functioning for quality of life and acknowledges the topic is often neglected by clinicians. The guidelines recommend that patients are asked if they have any concerns about their sexual functioning and given the opportunity to discuss any problems they are experiencing. It is suggested that this is done

soon after discharge from hospital, and at six monthly and annual reviews. Brief recommendations made for individuals experiencing difficulties include an assessment of causes, reassurance around safety of having sex and referral to a “person with expertise in psychosexual problems” for unresolved difficulties.

The recent inclusion of sexuality in stroke policy and guidelines may not however reflect an actual change in practice. In an audit of practices in a stroke rehabilitation unit in Australia, McCluskey, Vratsistas-Curto and Schurr (2013) found a number of areas where compliance with available guidelines was low. Management of sexual functioning was found to be one of the particular areas of recommended practice that was not being adhered to and staff appeared resistant to changing this. Barriers to the implementation of guidelines varied between professionals but the key barriers identified across the sample were professionals’ beliefs that they were not capable of carrying out the recommendations or that patients would not be able to engage in the recommended intervention, beliefs about possible adverse consequences of carrying out a guideline and a lack of prompts to remind professionals to carry out these recommendations. Other barriers were professionals’ perceived lack of knowledge and skills, low motivation to carry out the guidelines and the lack of necessary resources. In relation to recommendations regarding providing advice around sexuality, participants were found to hold unhelpful beliefs about the negative consequences of asking patients about sexuality and importance of sexuality to the stroke survivors. Some participants admitted to intentionally avoiding the topic. The authors recommended training in this area focus in increasing skills and ways to communicate about sexuality.

Stroke Survivor Views

Evidence suggests that sexuality is important to stroke survivors (Stein, Hillinger, Clancy & Bishop, 2013). They wish to discuss sexual issues (Conine & Evans, 1982), are interested in receiving sexual counselling or education (Choi-Kwon et al., 2005), and report that achieving intimacy is an important life goal (Conrad, Doering, Rief & Exner, 2010). However, for some participants the topic of post-stroke sexuality was never discussed as part of their rehabilitation and it was only within the context of a research study that the topic was raised. For example, Hamam (2011) described a case study in which an individual gained access to successful support for post-stroke sexual dysfunction following their involvement in a research study. In a questionnaire study of 27 participants, Chadwick et al. (1998) found that none had received any information relating to sex during their rehabilitation. In a study involving 37 spouses of stroke survivors, none were found to have received any education from rehabilitation professionals regarding post-stroke sexual activity (McCormick, Riffer & Thompson, 1986).

Schmitz and Finkelstein (2010) asked stroke survivors and their spouses about their rehabilitation needs in relation to sexuality. Participants wanted rehabilitation professionals to discuss sexuality with them and to provide information. They acknowledged they found it difficult to talk about sex and thought the discussion should be initiated by professionals, who should be open to talking about the topic and help them to feel comfortable. All of the participants described changes relating to sexuality, but very few had had any discussion about sexuality with a professional during their rehabilitation. Participants also highlighted the need for education tailored to individual needs, provided through contact with a rehabilitation professional and via written material. The importance of when to provide this information was also highlighted, with participants suggesting that information after the

acute phase of hospitalisation, when people are thinking about returning home, would be beneficial. Additionally, it is important to note that participants were aware of the avoidance, discomfort and lack of knowledge shown by staff in approaching sexual matters, believing that they showed the same level of uneasiness talking about sex as the participants themselves.

In a recent online survey of 38 stroke survivors, Stein et al. (2013) found that 75% of male and female stroke survivors experiencing sexual dysfunction wanted to receive relevant information about these difficulties. However, 81% reported getting insufficient information regarding sexuality during their rehabilitation. When asked about their preferences for receiving information, participants varied in the source of information they preferred, with some preferring written material and others preferring counselling from a healthcare professional. The majority of participants thought information should be provided within the year post-stroke, with some stating a preference for receiving support whilst still in hospital. The doctor was the preferred professional to provide counselling, followed by nursing staff. The study highlights the need for individualised care relating to sexuality, as participants differed in how much information they wanted, the source of this information and when they felt the information would be helpful.

Interventions and Support

Despite evidence that sexual problems are common after stroke and often an unmet rehabilitation need, there has been little research published about specialised support or interventions. Reviews of the educational needs of stroke survivors and their carers have identified the need for education programs on sexuality (Hafsteinsdóttir, Vergunst, Lindeman & Schuurmans, 2011), and researchers of post-stroke sexual functioning have repeatedly suggested a need for support, advice and counselling (Daniel et al., 2009;

Thompson & Ryan, 2009; Duits et al., 2009, Giaquinto et al., 2003; Murray & Harrison, 2004).

To date only one study has been published on sexuality-based interventions within stroke rehabilitation, although similar interventions have been developed in other areas of rehabilitation such as Spinal Cord Injury (Tepper, 1997). Song, Oh, Kim and Seo (2011) developed and measured the efficacy of a sexual rehabilitation program for stroke survivors and their spouses in South Korea. The program included educational information, tips and strategies and counselling for fears relating to sexual activity. The program was delivered individually to 12 couples prior to hospital discharge, and accompanied by a booklet. When compared to a control group, the treatment group showed a significantly greater degree of sexual satisfaction and frequency of sexual activity, but not an increase in sexual knowledge. The authors commented that knowledge may not be an appropriate measure of the effectiveness of the intervention, considering the other improvements experienced. Given the effectiveness of the intervention, the authors suggest that their program could be used as a guideline for post-stroke sexual rehabilitation.

However, in a pilot study of a Canadian self-management group for carers of stroke survivors where sexuality was included as a module, participants suggested it be replaced with other topics they perceived as more important (Mores et al., 2012). Participants in this study had been carers for an average of 36 months, so may have had very different needs to couples approaching discharge. These studies suggest that in some services efforts are being made to address post-stroke sexual concerns but also highlight that participant needs might vary due to a range of factors including level of independence. In a review of out-patient follow-up at an Israeli stroke clinic, it was found that those reporting sexual dysfunction

were being referred for “sexual rehabilitation”, although no details are given of what this entailed (Greenberg, Treger & Ring, 2004).

In the absence of specific interventions and support, stroke survivors may gain support around sexuality post-stroke from educational resources. The provision of written information is recommended in many clinical guidelines relating to stroke rehabilitation (European Stroke Organisation, 2008). Hamam, McClusky and Robbins (2012) completed a content analysis of sexuality-related educational materials available online from reputable stroke and health organisations. They found that available information often described the potential sexual problems following a stroke in line with available evidence. However, information on solutions and support was varied and was often found to be overly general, vague and not backed up by research. Written material frequently recommended stroke survivors to “talk to your doctor” and suggested that professionals would be able to provide support. The authors commented that this does not reflect the evidence that healthcare professionals may struggle to discuss and address sexual concerns, and this advice may give stroke survivors an unrealistic expectation of how open and helpful a professional may be. In their review Haftsteinsdóttir et al. (2011) suggested that whilst written information is important, it may not be beneficial if provided in isolation from discussion and follow-up with a professional. Additionally, cognitive and visual deficits may limit some stroke survivors from accessing written information.

Healthcare Professionals’ Views

Evidence from stroke survivors suggests that healthcare professionals working within stroke rehabilitation are not providing information and support around sexuality issues. To date only a small-scale pilot has investigated the experiences of health and social care professionals in addressing sexuality issues. McLaughlin and Cregan (2005) gave

questionnaires to 17 staff members of the hospital and community stroke teams in Northern Ireland. They found that many of the participants had been approached for advice about sexuality, but staff reported lacking experience and training in the area of sexuality, which presented a significant barrier to addressing service-users' concerns. Participants were also often not aware of the procedures for addressing sexual concerns and if protocols existed. A clear need for training that would improve levels of comfort, knowledge and skill was identified. Participants expressed a need for training to cover the range of sexual consequences of a stroke and referral procedures as well as skills in communication and psychosexual counselling. This study was carried out on a small scale and the questionnaire format may have limited participants' ability to express their views, but it has highlighted a significant area of need for staff.

Support for Healthcare Professionals

Drawing on the available research evidence, clinical documentation and clinical experience, Kautz (2007) has produced a summary of information and practical advice about sex and intimacy post-stroke, for nurses working within rehabilitation. He outlines the responsibility of nursing staff to provide information and support relating to sexuality, whether stroke survivors may use it or not. The document summarises the common impact of a stroke on sex and intimacy, including the changes in sex and intimacy associated with co-morbid conditions common in stroke survivors, including diabetes and hypertension. The document outlines information and advice nurses could give, including strategies to manage fatigue, poor body image and considerations for catheter users. The article also directs nurses to a range of information leaflets and other resources that could aid them in feeling better informed and equipped to manage patient concerns. Hall (2013) has also produced a similar review of the literature and model of care that could be used by nurses.

The PLISSIT model (Annon, 1976) is a tool that guides healthcare professionals in assessment and intervention for sexual problems. It proposes four levels of intervention, through which the majority of sexual problems can be resolved. It moves from briefer to more intensive interventions, with the later stages requiring a greater level of knowledge and experience in the professional. The stages are “Permission Giving”, “Limited Information”, “Specific Suggestions” and “Intensive Therapy”. PLISSIT has been advocated for use by staff working within stroke rehabilitation (Hall, 2013, Shah, 2009, Kautz et al., 2009) and has been used as a focus of sexuality training for staff working in the area of neurodisability (Simpson, Anway, Wilson & Bertapelle, 2006). The PLISSIT model has now been extended to recognise the importance of “Permission Giving” as a core component throughout all of the stages (Taylor & Davis, 2007).

Limitations of Research

The main limitation of the research on sexuality within stroke rehabilitation is the paucity of relevant studies. The available studies give useful indications of areas for future research and intervention, but as they are often small in scale they may not be generalisable to other stroke rehabilitation services. Previous research needs to be replicated and expanded to reflect the diversity of practice in rehabilitation settings.

Future Research

There is overwhelming evidence that difficulties relating to sexuality after stroke are common. Research has repeatedly suggested that support should be provided to service-users, such as educational interventions or counselling. However, despite changes in national policies and guidelines to highlight the importance of sexuality within stroke rehabilitation, evidence suggests that healthcare professionals rarely approach the area

with service-users and feel uncomfortable and ill-equipped to address sexual concerns. This is a major barrier to the needs of service-users being met. It will not be possible to develop and implement effective interventions for service-users whilst staff are unable to put them into practice. A greater understanding is needed of the perspectives of staff working in stroke rehabilitation. This should include how they approach the area of sexuality and how barriers and enablers operate on their ability to address issues in this area of service-users' lives. Qualitative methods can be used to gain a greater understanding of these areas, without researchers imposing their own concepts of sexuality and how it should be addressed, which may not fit with actual clinical practice. Greater understanding of staff perspectives can help to inform interventions for staff which will support them to address the needs of service users more effectively.

Research into the sexual consequences of stroke must also seek to include the entire spectrum of those who experience a stroke, and consider how sexuality may be impacted and experienced by different individuals, including those with different stroke-related impairments and those who have been so far neglected in the literature. Researchers may benefit from taking a positive focus and investigating the experiences of those who experience sexual satisfaction after stroke, or adapt to post-stroke sexual changes. These perspectives may inform understanding of what will best support other stroke survivors.

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MAJOR RESEARCH PROJECT

ALEXANDRA F. RICHARDS

Section B: A grounded theory of healthcare professionals'
engagement with sexual concerns within stroke rehabilitation

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A GROUNDED THEORY OF HEALTHCARE PROFESSIONALS' ENGAGEMENT WITH SEXUAL
CONCERNS WITHIN STROKE REHABILITATION

3

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Abstract

Post-stroke sexual difficulties are common but sexuality is an area frequently neglected within stroke rehabilitation. This study aimed to explore the process by which healthcare professionals approach and work with the topic of sexuality within stroke rehabilitation. This was hoped to improve understanding of why current guidelines around addressing post-stroke sexual issues are not followed, and what would support professionals to meet patients' needs. Ten healthcare professionals working within stroke rehabilitation were interviewed, covering a range of disciplines and settings. The data were analysed using grounded theory methodology. Fourteen major categories were co-constructed from participants' data and a theoretical model was developed. Although the majority of participants rarely engaged with sexual issues, they adopted both direct and indirect strategies for engaging with the sexual concerns of their patients. Concerns were usually addressed through the provision of information and supportive conversation with a professional. Professionals' own personal level of comfort with the topic of sexuality interacted with a series of barriers to limit opportunities for engaging with sexual concerns. These barriers included environmental factors relating to the context of stroke rehabilitation, professionals' perception of lacking abilities and unhelpful attitudes towards patients and sexuality. Positive and inclusive attitudes towards sexuality and professional roles and building a strong therapeutic relationship facilitated professionals taking action. The findings are considered in relation to existing guidelines and research, and the clinical implications for rehabilitation and staff training are discussed.

Key words: Stroke, Sexuality, Rehabilitation, Staff, Training

A Grounded Theory of Healthcare Professionals' Engagement with Sexual Concerns

Within Stroke Rehabilitation

Stroke is one of the greatest causes of death and disability worldwide (National Stroke Strategy, 2007). Advances in stroke care mean a greater number of people now survive a stroke, but many live with long-term disabilities (National Audit Office, 2010). Sexuality has been increasingly recognised as both an important part of human life and as a part of holistic healthcare (Department of Health, 2010; Royal College of Nursing, 2001). "Sexuality" is a broad term that encompasses sexual roles, activity, identity, intimacy and pleasure, amongst other aspects (World Health Organisation, 2004). Ability to express sexuality and experience sexual health is an indicator of good quality of life (Chadwick, Saver, Biller & Carr, 1998).

Sexual Issues Post-Stroke

Research indicates that sexual problems post-stroke are common, including difficulties related to arousal, orgasm, decreased sexual desire and satisfaction (Bugnicourt, Hamy, Canaple, Lamy & Legrand, 2013; Yilmaz, Gumus & Yilmaz, 2013). Less obvious sexual difficulties may include being fearful of engaging in sexual activity and changes in a couple's relationship, such as reduced intimacy and changing roles (Thompson & Ryan, 2009). These difficulties can impact the stroke survivor, and also impact on their partner (Schmitz & Finkelstein, 2010). In a review of the literature, Bugnicourt et al. (2013) reported the prevalence of problems relating to sexual functioning post-stroke was between 17 and 42%, with 30% of their own sample (N=104) reporting "impaired sexual activity".

Post-stroke sexual difficulties may relate to some of the direct consequences of the stroke, such as hemiparesis which impacts on movement in sexual activity (Rees, Fowler & Maas, 2007). Research suggests that post-stroke sexual dysfunction is rarely a direct result

of brain damage, and often relates more to psychosocial factors (Rosenbaum, Vadas & Kalichman, 2013). These include adapting to changes in functioning and loss of role, depression and changes in self-image and how a couple's relationship dynamic may be changed by the stroke and potential caring needs.

Sexuality within Stroke Rehabilitation

Research exploring the experiences of stroke survivors has found that during rehabilitation healthcare professionals (HCPs) rarely discuss sexuality or provide information, although many participants reported that this was wanted (Schmitz & Finkelstein, 2010; Stein, Hillinger, Clancy & Bishop, 2013). The topic of sexuality is often absent from rehabilitation and service-users are left unprepared for the difficulties that they may experience.

The importance of post-stroke sexuality has been recognised and reflected in recent stroke policy. The National Clinical Guidelines for Stroke (2012) recommends that patients' sexual functioning is assessed and reviewed regularly, and that support is provided if required. Research into post-stroke sexual functioning has advocated the need for information provision, education and counselling for stroke survivors and their partners (Daniel, Wolfe, Busch & McKeivitt, 2009; Giaquinto, Buzzelli, Di Francesco & Nolfé, 2003). To date only one study has been published on an (educational) intervention aimed specifically at improving post-stroke sexual outcomes, developed in South Korea (Song, Oh, Kim and Seo, 2011), which was found to improve sexual satisfaction in couples.

Stroke rehabilitation is not the only field where sexual issues may be under-recognised and not addressed. Evidence suggests that the topic is also frequently neglected in other areas of rehabilitation and healthcare (Haboubi & Lincoln, 2003). Risk of stroke increases with age and older adults and those with disabilities are marginalised groups and

their sexuality is often stigmatised or denied (McRuer & Mollow, 2012; Simpson, 2001).

These factors may have increasing importance in the stroke rehabilitation setting. Research carried out regarding staff approaches to sex in other healthcare settings involving disability, long-term conditions and older age may have parallels with the stroke healthcare setting.

Healthcare Professionals' Perspectives on Working with Sexuality

In a review of qualitative studies of HCPs' experiences of discussing sex with service users in various services, including cancer and rehabilitation, in the UK, Dyer and das Nair (2013) identified several key themes. These included healthcare organisation factors (such as lack of resources and time) and factors personal to the HCP (including attitudes and knowledge). The majority of the participants considered that discussing sexuality was important, but it was not routinely discussed and the responsibility was often left to the service-user to initiate discussion. Professionals worried about "opening a can of worms" (p7) when they did not have the resources to address concerns. Personal discomfort was also a frequent finding. Similarly in Guthrie's (1999) study of nurses in a surgical setting, participants were reluctant to bring up the topic of sexuality and felt it was the patient's responsibility to initiate discussion. Organisational factors such as lack of time and workload demands and personal factors such as upbringing were also found to make conversations about sex difficult. Guthrie concludes that staff training is needed, but increasing knowledge may not be sufficient if nurses are not in a position to use such knowledge due to lack of general communication skills and working in a setting that does not facilitate discussion of sexuality.

Sexuality Training for Healthcare Professionals

The need for staff training has frequently been recommended by researchers, but if staff are uncomfortable working with sexual issues and are working in an environment that

stigmatises sexuality, they may not be able to make use of factual information in practice (e.g. Guthrie, 1999).

Sexuality training programs have been developed in other healthcare settings (e.g. Simpson, Anwar, Wilson & Bertapelle, 2006). Researchers have shown increases in staff knowledge and comfort following these training courses (Fronek, Booth, Kendall, Miller & Geraghty, 2005). However, no stroke-specific training has been reported in the literature. Moreover, stroke-specific training will need to take into account factors unique to the stroke rehabilitation setting and how factors already identified in the research, such as level of comfort and knowledge operate to limit and enable staff to meet the needs of stroke survivors.

Rationale for Study

There is a wide body of literature covering the impact of stroke on sexuality. The need for support for service-users has been repeatedly recommended, and the behaviour of HCPs has been proposed as a significant barrier to meeting these needs. However, research that has actually focused on stroke professionals' perspectives on sexuality and their experiences of working with this topic has been very limited. It is not clear if the findings from other healthcare settings are applicable to the stroke setting.

McLaughlin and Cregan (2005) carried out a pilot study of the views of 17 HCPs on sexuality within stroke rehabilitation. They found that participants lacked experience and training to address post-stroke sexual issues. Although making a valuable contribution to a neglected area, the restrictive structure of the questionnaire limits a more detailed understanding of staff's perspectives and how factors such as "level of training", "organisational limitations" and "personal discomfort" might operate. The study

recommends staff training, but from the results it is not clear how training might be used to reduce barriers and to increase staff's ability to address patient concerns.

The present study aims to build on McLaughlin and Cregan's (2005) preliminary findings, focusing on how staff think, feel and act in relation to the topic of sexuality within their work and with their client group. The aim of this exploration would be to understand how barriers operate to addressing the sexual concerns of service-users, and what facilitates these interactions. A qualitative approach that includes theory development can generate knowledge specific to the experiences of staff working within stroke rehabilitation. It is hoped this knowledge will be used to inform clinical practice and policy, and to develop appropriate and successful interventions for staff teams, which will be of benefit to patients.

Research Questions

The present study aims to investigate the following questions:

1. How do healthcare professionals approach the topic of sexuality within stroke rehabilitation? With consideration of:
 - a. How sexuality is approached¹ within the stroke rehabilitation setting
 - b. How sexuality is approached in relation to stroke rehabilitation service-users (stroke survivors and their families)
 - c. How sexuality is approached in relation to the professional roles of staff working within stroke rehabilitation

¹ "Approach" is used here to mean "a way of dealing with someone or something; a way of doing or thinking about something such as a problem or a task" (Oxford Dictionaries, 2013)

Method

Design Overview

Grounded theory methodology was selected as an appropriate non-experimental method for developing an in-depth conceptual framework of an area where there has been little previous research and there is no guiding theory or hypothesis available to test. Grounded theory enables the generation of a theory grounded in the participants' own experiences and the context they are situated in (Charmaz, 2008).

The study used a qualitative design using semi-structured individual interviews. This involved the use of broad open-ended questions to enable following participants' spontaneous responses, avoid leading them and to collect detailed data about participants' subjective experiences. This was in line with grounded theory methodology (Charmaz, 2008).

It was necessary to carry out an abbreviated form of grounded theory methodology due to time constraints. This limited the capacity for theoretical sampling and theoretical saturation (Willig, 2013). Theoretical sufficiency was reached and this is considered appropriate in the absence of saturation (Dey, 1999).

Epistemological Position

The researcher took an interpretivist position (Urquhart, 2013). This approach, informed by Charmaz (2008), aims to study phenomena within their social settings and allow the participant and researcher to be involved in their own co-construction of meaning.

Participants

Inclusion criteria. Participants were HCPs who worked within stroke rehabilitation. The criteria were broad to represent the variety of professionals and background within multi-disciplinary stroke teams. Through consultation with stroke professionals it was

decided that participants must have at least six months of stroke rehabilitation work experience, so as to be sufficiently oriented to the context and client group.

Recruitment. Participants were recruited from five different services: two community neuro-rehabilitation services, a neuropsychology service, an inpatient stroke service and a community stroke service. The sample was self-selected, recruited through presentations by the primary investigator at team meetings. Information about the study was distributed to staff via email by the team managers.

Sample. Ten participants were interviewed in total, from the following professions: Rehabilitation Assistant (two), Nurse (two), Clinical Psychologist (two), Occupational Therapist (three) and Physiotherapist (one). Please see Appendix C for further participant details. They ranged in age from 32 to 50, and had between two and over 20 years of experience of working with stroke survivors. One participant worked in the inpatient setting, two participants worked in both the in-patient and community settings, and seven worked in the community alone. Four of the participants had experience of working in both inpatient and community rehabilitation settings.

Ethical Considerations

This research study was reviewed and approved by the University Ethics Committee (Appendix D). Approval was also granted from the Research and Development departments of four NHS trusts where recruitment was planned (Appendix E). Ethical practice was also guided by the BPS code of ethics and conduct (2009).

All participants were provided with an information sheet (Appendix F) and the opportunity to ask questions before giving written consent (Appendix G). Participants also completed a brief demographics form (Appendix H). The information sheet had also been given in the initial recruitment, to enable participants to anticipate the topics of the

interview. Following the interview participants were debriefed and given the opportunity to ask questions and discuss the research.

Procedure

An interview guide (Appendix I) was created with reference to the research questions and McLaughlin and Cregan's (2005) questionnaire. The interview was piloted on one research supervisor, (a HCP working within stroke rehabilitation) in order to check it covered the relevant areas and to consider wording.

The interview topic was considered to be sensitive and some general questions about the participant's role and work were included at the start to build rapport and the researcher used prompts, summarising and asked for clarification in order to facilitate participants to elaborate on their experiences and to maintain the conversation (Smith, Harre & van Langenhove, 1995). Interviews lasted between 17 to 51 minutes in length.

Data Analysis

Interviews were audio recorded and transcribed verbatim. The process of moving from the data to theory generation was carried out through several stages (Glaser, 1978), as summarised by Urquhart (2013):

1. After each interview brief memos (Charmaz, 2006) were written on key concepts and areas for further investigation and these were held in mind for the next interviews.
2. Line by line open coding. This was carried out for the first six interviews. Computer program Nvivo 9 was used to manage coding. Please see Appendix J for the coded transcript of the first interview and Appendix K for open coding examples.

3. Selective coding. This involved focusing on the more frequent codes relevant to the research question and re-coding the data at a more conceptual level. The initial open codes were elevated to become more analytic and directional.
4. The interview schedule was developed to further expand on the developing concepts (Appendix L) and three further interviews were carried out and then analysed using selective coding.
5. Theoretical coding. Substantive codes were developed and assimilated into conceptual categories and the relationships between them explored. Constant comparison technique (Glaser & Strauss, 1967) was used to monitor similarities in the data. Memo writing (Charmaz, 2006) was used to further define and explore emerging concepts (Appendix N). Theory generation was facilitated by memos and initial diagramming of the relationships between concepts (Strauss, 1987, see also Appendix O). Appendix P shows the coding process.
6. Theoretical sampling. One further interview was carried out with a participant with a role that had emerged as important in the earlier interviews.
7. This final interview was also used to try out the emerging theory and to further refine categories. Data from this interview suggested that the categories adequately covered the participant's experience.

Quality and Validity

As an interpretivist position was adopted, it was acknowledged that the researcher plays an active role in co-constructing meaning and interpreting the experiences of participants. The researcher had worked within stroke rehabilitation and was therefore

likely to share some similar work experiences and understanding with the participants, and this could influence how the participants' data was viewed. Additionally, the researcher held a liberal attitude towards sexuality and believed this to be an area significantly neglected within healthcare, and this too had potential to shape how the data was interpreted. As a psychologist, there was also potential for the researcher to identify with the data from the psychologist participants and interpret this in a different way to that of the other participants. The researcher kept a reflective diary (Appendix M) throughout the study. This was used to explore the researcher's position and assumptions and how this might impact on the interpretation of the data (Charmaz, 2006). This was also reflected on in supervision.

Guidelines for quality in qualitative research (Mays & Pope, 2000, Appendix R) were used to guide the research. A section of transcript was coded by a research supervisor to monitor the influence of the researcher's position on the coding. A grounded-theory based peer study group was also used to explore the credibility of coding and discuss appropriate labelling of categories. Participants' own "in vivo" data (Strauss, 1987) was used in memos and naming concepts in order to keep the analysis close to the participants' own experiences. Research supervisors also provided guiding on coding throughout the process of analysis.

Results

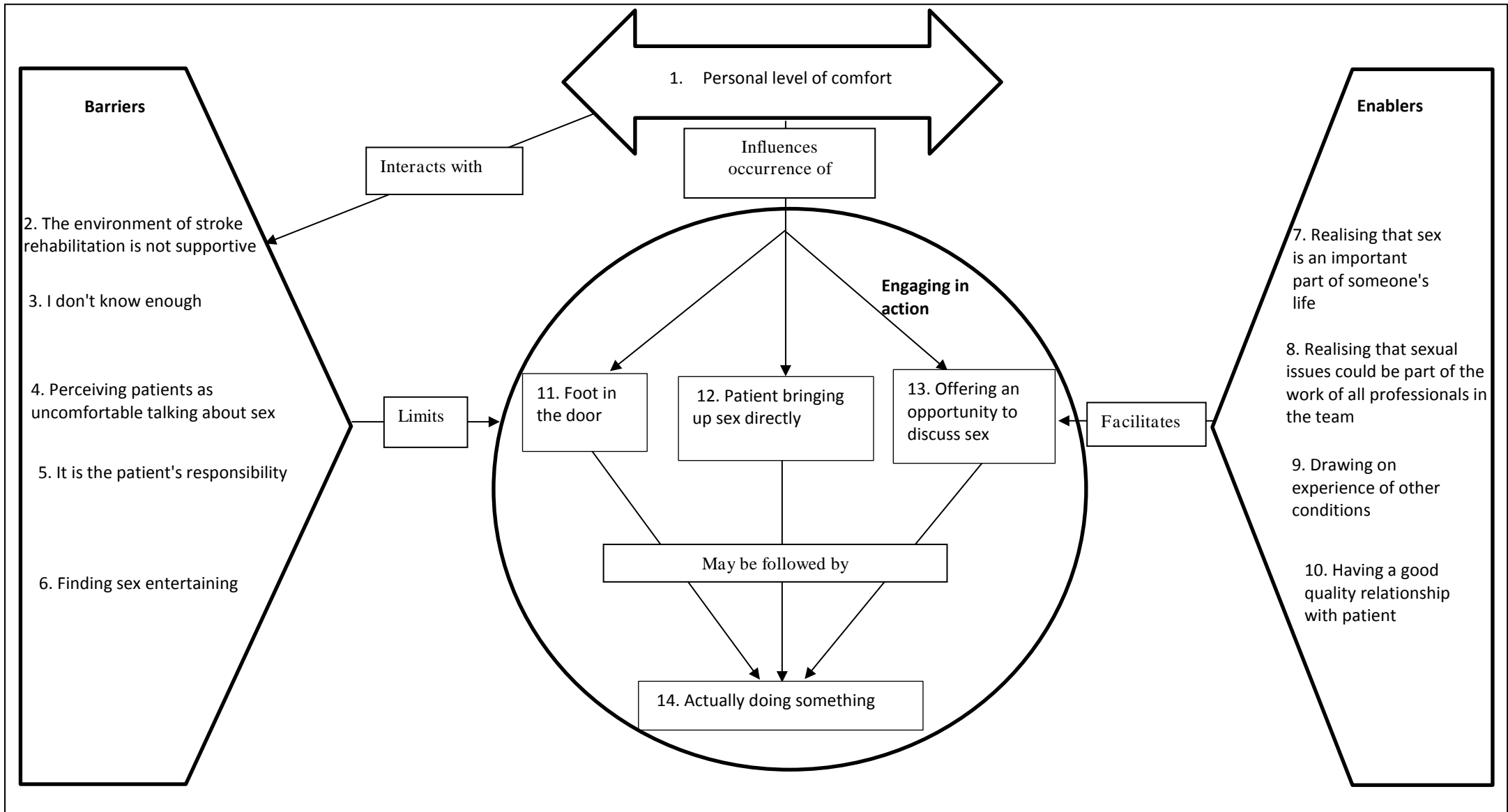
The analysis identified four higher-level categories and 14 major, which together create a conceptual model of how HCPs in stroke rehabilitation engage with sexual concerns. The action that HCPs took to approach and address patients'² concerns ("Engaging

² The word "patient" is used here to refer to stroke survivors using stroke rehabilitation services as this was the word commonly used by participants

in action”) was influenced by their own level of comfort with the topic of sexuality (“Personal level of comfort”, on a continuum) which interacted with a series of factors (“Barriers”) which limited HCP’s opportunities and ability to take action. Additionally certain factors (“Enablers”) acted to facilitate interactions with patients. Figure 1 outlines this model and is followed by an exploration of the categories and their relationships to each other. Appendix Q lists all the components with examples from the data.

Participants commented on both their own experiences and their observations of other professionals in their teams. Results relating to “HCPS” therefore refer not only to the participants, but other professionals also.

Figure 1: How healthcare professionals in stroke rehabilitation engage with the sexual concerns of their patients



1. Personal Level of Comfort

This category represents a continuum of how comfortable the HCP feels about the topic of sexuality. This impacts on how they act in response to situations relating to sexuality that arise in their working environment.

Participants spoke of aspects of their own life and experiences, including upbringing, which seemed to contribute to how comfortable they were to discuss sex in their work environment.

"Well I've seen all that anyway so just talking about sex... you know it's not gonna bother me" (Participant 9)

The ease at which participants spoke about sex in their personal life seemed to directly impact on their level of comfort talking about sex at work, with those who identified themselves as more "conservative" being less likely to discuss sex with patients than those who considered themselves "open". Ultimately, participants own character and personality traits were seen as having a key impact on their resulting level of comfort with the topic of sexuality.

"I mean I'll talk to anybody! ...And that's I that's my personality that's it I'm guessing what more than anything else" (Participant 10)

An individual's personality and life experiences may be considered to be relatively constant factors beyond the influence of contextual factors or training. As one participant put it *"I think ... that's a personality thing you can't teach people to be comfortable about talking about sex"*.

A second important factor in determining levels of comfort for participants seemed to be around level of work experience. The majority of the participants had little experience of sexual issues arising in their work. They related their own discomfort to a lack of

opportunities to learn how to work with sexual issues. The participants who did feel more comfortable often related this to having longer careers and cumulative experience.

"You don't do (number) years of nursing um and start to be phased by things you know"

(Participant 10)

The most comfortable professionals were often more experienced and were known by others to be able to work with sexual issues and provide support to others around this. Personality, personal and work-based experiences combined to create a sense of comfort that had a key influence on how HCPs behaved at work.

Barriers

The higher-order category "Barriers" contains categories that limit, impede and reduce the occurrence of the HCP engaging in action. These barriers interact with personal level of comfort, so a less comfortable individual may be more limited by these barriers.

2. The environment of stroke rehabilitation is not supportive. The context that HCPs work within acted as a considerable barrier to addressing sexual concerns.

The time-scale of rehabilitation limited opportunities for sexual issues to arise and be addressed. Early rehabilitation often focused on increasing the patient's independence to facilitate discharge and living at home. Professionals tended to be more involved while patients were in hospital and immediately after hospital discharge, with contact decreasing over time. Participants considered that sexual issues were most likely to come up after at least six months after hospital discharge, at which point professionals might be less involved.

"We meet them quite soon, I guess at that point ... they've not taken on board exactly what stroke means to them in their everyday way of life" (Participant 2)

Participants reported that it was important to focus on the "immediate needs" and this did not leave a clear time for addressing sexuality.

"They've had a major life-changing event and really it's about making sure that they're going to get out of hospital rather than... thinking about the sexual kind of things..."

(Participant 4)

However participants' assumptions about what patients' priorities were did not always correspond with clinical practice. Several participants recalled times when sexuality had actually been a priority for a patient early on.

"Her goal was to have sex ... she had she had some quite serious disability ... so that was quite a long way off" (Participant 1)

The environment participants worked within also provided several practical barriers to discussing sexuality with patients. The questions HCPs routinely asked of patients were guided by standard assessment forms. The form legitimised asking a large series of questions, including "sensitive" topics such as incontinence, but did not include a question about sexuality. It was not clear how and when such a question could be asked.

"A simple thing is it's not on the forms so we don't have to it's not on our assessment criteria so we don't ..." (Participant 2)

The environments in which participants worked (including the inpatient ward and seeing patients in their family homes) often did not feel like a suitable place to have a discussion about sexuality due to lack of privacy. High professional workloads also limited the time available to participants to consider sexual issues.

"We are under pressure to see more people and get a lot of... through-put" (Participant 8)

Often there was pressure to see patients quickly and to discharge. This left little time for dealing with less "essential" topics and facilitating conversations about sensitive areas.

Lack of time also limited participants' time in which they could inform themselves about areas that were new to them.

3. I don't know enough. Participants' perception of their own knowledge and skills limited their ability to engage with the sexual concerns of their patients. The less capable the HCP felt the more reluctant they were to engage with a patient regarding a sexual issue. Participants experienced uncertainty in how to manage sexual issues and believed that they lacked the necessary knowledge and abilities to proceed. They were often unsure how to go about bringing up and speaking about sexual issues with patients and frequently expressed that they would not know how to proceed if a patient brought a sexual concern to them.

"Some of the therapists were saying 'Well you know I I wouldn't know what to do'"

(Participant 6)

There was no available policy or procedure for dealing with these types of issues. Knowing that they could not provide support made participants reluctant to ask about sexual areas, as one participant put it: *"What's the point of bringing it up if you're not going to do anything"* (Participant 2). Sexuality was seen as an area of "specialist" knowledge and a case that involved a sexual element seemed to be always viewed by the team as "complex". Many participants expressed a need for training that would give examples of how to speak about sex and address concerns. Additionally some uncertainty existed in teams as to which HCP was best equipped to deal with sexual issues and whose responsibility this was.

"I honestly don't know who it should be that addresses it"(Participant 5)

Roles within the multi-disciplinary team are often flexible and this could lead to confusion about who was covering which aspect of the patient's care.

Participants frequently reported that they were not knowledgeable or experienced with working with sexuality issues. However, when discussing their work broadly participants often referred to areas that could be considered broadly related to sexuality, such as relationships, body-image, gender-related roles and identity. Participants tended to conceptualise "sexuality" and "sexual issues" as relating only to sexual activity, and this was seen as a separate area to their other work.

4. Perceiving patients as uncomfortable talking about sex. Participants tended to assume that patients would be uncomfortable speaking about sexual topics, and this made them resistant to approaching the subject.

Participants considered that it was common for people to not feel comfortable speaking about sexual topics, and that bringing up the topic had the potential to distress a patient. There was anxiety to avoid upsetting the patient and a concern existed that bringing up sex could impact negatively on the therapeutic relationship and jeopardise rehabilitation.

"I feel like 'Am I going to offend you by... talking about this?'" (Participant 6)

Those patients who are comfortable speaking about sexuality were seen as an exception to the majority.

The patients seen within stroke rehabilitation tended to be older and another commonly held belief was that older people were less likely to speak about and be open about sex. This was perceived as relating to a more conservative time when patients grew up and being unaccustomed to speaking more openly about sex.

"I think um the age group generally that we deal with is of an age where they didn't talk about sex anyway" (Participant 4)

Sex was also viewed as of lower importance to older people. Participants were more likely to consider sexual issues if they were working with a younger patient.

"I know it's a real stereotype but you can imagine perhaps a younger man who's just had a stroke being that being something really quite at the forefront" (Participant 7)

Participants often realised that these attitudes were ageist, but acknowledged that they did impact on their practice.

Despite these beliefs about patients often being held as "fact", participants were rarely able to give examples of when speaking about sexuality had been distressing to a patient (of any age) or impacted negatively on the clinical work.

5. It is the patient's responsibility. Participants expected patients to initiate a conversation about sexuality.

"I wouldn't bring it up unless they did" (Participant 5)

Participants expected that if sexuality was a concern to the patient then they would bring it up, and they did not need to encourage the patient to do so.

"If people want to talk about it they do" (Participant 4)

6. Finding sex entertaining. The topic of sex was often treated as amusing by HCPs.

Sex was often considered in a humorous or otherwise non-serious manner amongst HCPs. When the topic of sex was raised it often elicited joking and laughter amongst staff, and cases that involved a sexual element were often talked about and spread amongst the group.

"It was quite well-known and I felt that that must have been quite difficult for her actually you know knowing that everybody knew"(Participant 3)

This behaviour was echoed in the interviews where participants often laughed in the context of speaking about sexuality, especially when it came to discussing specific details.

Laughter appeared to reflect finding the topic amusing, but also managing feelings of awkwardness and embarrassment. Professionals seemed to enjoy joking and gossiping about sex, but some participants expressed concern for how this might affect interactions with patients.

Enablers

The higher-order category "Enablers" contains the categories that enhance, facilitate and increase the frequency of professionals engaging in action.

7. Realising that sex is an important part of someone's life. Some participants had come to appreciate the role sexuality plays in someone's life and the importance it held.

"As a practitioner reminding myself that this is an important part of people's lives"

(Participant 6)

This motivated them to consider the area, inform themselves and support patients. Sometimes this realisation came from experience with patients and being confronted with the reality that sexuality was important to them. At other times this was a more general reflection on the area of sexuality.

8. Realising that sexual issues could be part of the work of all professionals in the team. When participants reflected that all the different professionals within the multi-disciplinary team could play a role in supporting a patient with sexual issues, this motivated them to engage with patients around these areas.

Participants aimed to provide holistic care and saw that sexuality was a key part of someone's life and identity. When considering who in the team could speak with a patient about sexual issues or support them, there was general agreement that this role could be taken up by any and all staff members and participants considered what their own discipline could contribute.

"I don't think it matters who it is so long as you know they are open and honest and um and feel comfortable doing it" (Participant 10)

Regarding actually addressing sexual concerns, participants were also able to nominate particular professionals who they saw as holding the knowledge and skills to address sexual issues, depending on the type of difficulty.

This category reflects participants' own words, emphasising that professionals saw that everyone "could" and "should" take part, but that this was not the reality of practice.

"Well within our training it was definitely touched on that we should address it... if it was a goal that patients ... I can't see why it couldn't be us but..." (Participant 5)

This discrepancy between "ideal" and "actual" practice encouraged participants to consider changing their own behaviour.

9. Drawing on experience of other conditions. Participants frequently had little experience of working with sexual issues within stroke rehabilitation. They had more commonly come into contact with these issues working with other patient groups, and they used this experience to inform their thinking.

"Um they (sexual issues) have certainly come up within my work ... because we do neuro-rehab in general there's quite a few people with MS" (Participant 7)

In particular participants drew on experiences of younger patients with neurological conditions such as multiple sclerosis and traumatic brain injury when considering how to work with stroke patients.

10. Having a good quality relationship with patient

Participants identified that it was important to have a strong relationship with a patient before the patient would feel able to bring up a sexual issue.

When referring to a "good" relationship with a patient, participants referenced subjective feelings of closeness and building a rapport. The patient feels understood and comfortable with the professional, so feels able to speak openly to them about their concerns. In particular this facilitates the patient in bringing up sensitive issues such as sexuality. Often having contact over a longer period of time facilitated the forming of a better therapeutic relationship, and certain professionals (such as rehabilitation assistants and psychologists) were more likely to have more frequent contact with the patient or over a longer period of time.

"You have seen the stroke team for much longer they've been visiting you a couple of times a week you feel much more able to disclose something more difficult" (Participant 6)

Patients with complicated issues and also those with less social support were also more likely have greater levels of professional contact.

Participants also discussed how particular qualities of the professional might impact on the building of a relationship. Some professionals were described as seeming to project an attitude of being open-minded and approachable, communicated through their speech and behaviour. This facilitated the patient in feeling comfortable to speak to them about sexuality.

"Patients feeling that they can ask and you having the right kind of um you're projecting um a kind of um attitude that people can ask and you're not going to be offended or embarrassed " (Participant 4)

Additionally, some participants spoke about the altered dynamic between a professional and patient when there are particular similarities or differences in characteristics.

"He was very suspicious of me coming in because I'm a psychologist but also because I'm a young woman" (Participant 6)

Age, gender and race were particularly mentioned and it was considered that the patient would feel more comfortable speaking to a professional they shared characteristics with.

These factors could combine in different ways to produce the type of therapeutic relationship that created a comfortable environment for a patient to express sensitive concerns.

Engaging in Action

It seemed that participants' willingness to engage in behaviours that supported a patient's sexual concern was influenced not only by their level of comfort, but by the wider barriers and enablers discussed above. These interact to influence how likely it is that a professional will engage with a sexual issue. When this did occur, participants behaved in particular ways in relation to the sexual issue which are outlined below:

11. Foot in the door. This category refers to the indirect means by which a HCP may bring up the topic of sexuality with a patient.

Participants described how discussion of another concern might provide a means of leading into speaking about sexuality. More "routine" topics that might serve as a "starting point" for moving on to sexuality included continence, body movement, relationships and sleeping arrangements.

"From a more physiological point of view I... to think about it like that makes it slightly easier um and then ... That almost opens up an avenue for conversation with a patient ... that almost breaks the ice a little bit for them to ask things" (Participant 1)

Indirect language was used to allude to sexuality and facilitate the patient in bringing up a sexual topic. This included very open general questions and speaking tentatively about sex. At times the patient's behaviour prompted the participant that they wished to discuss sexuality. This included noticing patients making jokes, "loaded" comments and sexual references.

"It comes up in a kind of loaded answer that you can then say 'Oh are you talking about this?'" (Participant 4)

Sometimes these methods were chosen deliberately by the participant to facilitate the discussion of sexuality, but at other times they were unexpectedly used by the patient to lead into the topic. This indirect approach appeared to be more comfortable than a direct approach for participants, and was considered to be easier for patients also.

12. Patient bringing up sex directly. Participants were able to recall instances when a patient had actively brought up the topic of sexuality, made it clear that sexuality was important to them and that they desired support relating to this.

Questions and problems posed to participants often related to the safety of engaging in sexual activity after stroke, erectile function or setting a goal related to sexuality. This was not a frequent occurrence, but often it was done in a very open manner which sometimes took the participant aback. Often the participant did not feel in a position to address the matter, so needed to refer the patient on.

13. Offering an opportunity to discuss sex. At times the participant directly introduced the topic of sexuality and offered the patient the opportunity to discuss it. By this method the participant expressly gave permission to the patient to speak about a sexual matter and indicates that it is a legitimate topic for discussion.

Participants rarely asked patients a direct question about their sexuality, but in some instances (such as in relation to a particular referral) this felt appropriate. At other times the participant found ways of communicating to the patient that it was acceptable for them to discuss sexuality if they wished to do so. Including sexuality amongst other topics within material presented to the patient, indicated to them that sexuality was one of many areas covered by the service.

"It (sex) is actually written on the screen at some point so that might then give people permission probably to... bring it up" (Participant 7)

Participants discussed giving patients the opportunity to raise a sexual concern by mentioning the topic at an early meeting or letting patients use a form to communicate that they would like to receive information relating to post-stroke sexuality.

14. Actually doing something. Once the topic of sexuality has been brought up the HCP may follow this by taking action. These actions are represented by the category "actually doing something", a code named using participants' own words to reflect the movement from approaching and considering sexuality to taking steps to provide a solution.

Amongst the participants there was a split between the few who did feel comfortable and capable to address patients' concerns, and the majority who did not. The majority of the participants did not feel that they were in a position to address a patient's concern, and therefore directed the patient towards another HCP. This "passing it on" could involve "sign-posting" to a professional or service with expertise in sexual issues. At other times this action appeared to be an avoidant strategy in which an uncomfortable professional alleviated themselves of responsibility.

"You just tend to say 'Contact your GP'" (Participant 2)

The doctor (either the GP or stroke consultant) was frequently the person who the patient was passed on to and this was often seen as an important starting point for addressing a sexual issue.

"To start with they'd have to talk to their doctor" (Participant 7)

This appeared to reflect the view that sexual issues are a medical concern, and may also reflect that the issues most commonly brought to the attention of participants are seen as "medical" (safety of sexual activity and erectile dysfunction).

Participants were able to identify particular types of intervention that could be carried out by a particular rehabilitation HCP if required. This included intervention from a physiotherapist relating to movement involved in sexual activity and talking therapy provided by a psychologist. Few participants had actually engaged in these types of interventions but were aware that they could potentially be provided.

Contrary to the view that addressing sexual concerns required "specialist" input, those who did try to address patients' concerns often utilised generic, transferable skills. In response to a patient bringing up a sexual issue, participants who felt comfortable to do so might listen to their concerns, give the patient a space to speak about the issue and provide reassurance.

"I tend to talk them through it erm... I... I've never given them step-by-steps instructions but they've never required that they've just wanted to say 'Is it ok...?'" (Participant 10)

This subcategory is named with participants own words; this was not seen a specialist intervention or counselling, but "just" talking. This was seen as a non-specific skill that HCPs engaged in regularly without difficulty. Often what a patient required was the opportunity to express their concerns, rather than any further intervention. Another "generic" intervention was the provision of information. Often this involved provision of

leaflets from the Stroke Association. However the use of these varied. Sometimes they were given to the patient in isolation, and other participants used the leaflet to begin a conversation about sexuality. Not all participants were aware of the availability of these types of leaflets. The provision of leaflets in general is a routine way of providing patients and their families with information, but giving out the leaflet on sexuality is not regular practice.

More comfortable participants felt able to transfer their common clinical skills to supporting an individual expressing a sexual concern. Less comfortable professionals were more likely to doubt their abilities seek the support of a more "skilled" professional.

Discussion

Links to Research Questions

How is sexuality approached within the stroke rehabilitation setting? The findings suggest that the topic of sexuality is not actively legitimised and incorporated within stroke rehabilitation. Participants were often not aware of policy around post-stroke sexual difficulties and evidence suggests that often these are not in place (McLaughlin & Cregan, 2005; Mellor, Greenfield, Dowswell, Sheppard, Quinn & McManus, 2013). The concentration of professional energy early on in rehabilitation and the pressures on HCP contact time were not conducive to addressing sexual concerns, which tended to arise, within the context of a longer therapeutic relationship.

Participants rarely directly brought up sexuality, which corresponds with other accounts from patients (Schmitz & Finkelstein, 2010) and professionals (Mellor et al., 2013). However, participants more frequently used indirect means to approach the topic with patients. This approach was more comfortable for participants, and was perceived as more

comfortable for patients also. These findings are in contrast to the National Clinical Guidelines for Stroke (2012), which recommends that soon after hospital discharge, professionals ask every patient if they have any sexual concerns, and that this is repeated regularly. This recommendation does not appear to reflect practice and may not actually be appropriate whilst barriers limit professionals' ability to do so.

Some participants were also finding ways in which the topic of sexuality could be legitimised within the rehabilitation setting. This offering of opportunities to speak echoed the "Permission giving" stage of the PLISSIT (Permission, Limited Information, Specific Suggestions, and Intensive Therapy) model of sex therapy (Annon, 1971). This involves the professional giving the patient permission to discuss their sexual concerns and to engage in the sexual activity that is normal for them. The professional aims to convey that sexuality is an acceptable topic for discussion and create an open environment for discussions to occur. This type of intervention can be provided by staff of all levels and does not require specialist knowledge or skills.

How is sexuality approached in relation to stroke rehabilitation service-users (stroke survivors and their families)? Participants were concerned about building a relationship with the patient and not causing them unnecessary discomfort. This behaviour often appeared to be motivated by assumptions of how easily distressed patients were, which was not consistent with the reality of raising the topic of sexuality. Gott, Galena, Hinchliff and Elford (2004) also reported that primary care professionals avoided raising sexual issues with older patients due to the risk of causing offence, but few participants could actually give examples of this happening. Patients may find it embarrassing to talk about sex, but still wish to receive support (Gott & Hinchliff, 2003).

Participants did not express overtly negative attitudes towards older people and those with disabilities. However, sexuality was often considered to be of lower importance and a low priority to both of these groups, and these attitudes impacted on practice. This corresponds with the literature which has repeatedly found that older people (Bouman, Arcelus & Benbow, 2006) and also those with disabilities are treated as "asexual" (McRuer & Mollow, 2012).

How is sexuality approached in relation to the professional roles of staff working within stroke rehabilitation? Although there was agreement that all professionals within the multi-disciplinary team could play a role in supporting patients experiencing sexual difficulties, few participants actually engaged in this behaviour. Sexuality was often seen as a difficult area that required input from a professional with specialist knowledge. Often the doctor was seen as holding the necessary skill, although research exploring the attitudes of doctors has found that they also find it difficult to discuss sexuality (Gott, Hinchliff & Galena, 2004).

Participants perceived themselves as lacking the necessary knowledge and skills to speak about and address a sexual concern, as has been found with other HCP groups (Mellor, Greenfield, Dowswell, Sheppard, Quinn & McManus, 2013; McLaughlin & Cregan, 2005; Rubin, 2005). However the more comfortable participants (regardless of discipline) described utilising generic skills to support their patients. This involved providing a space for the patient to express their concerns, listening and providing reassurance. This is in line with the PLISSIT model (Annon, 1971) that suggests that for the majority of sexual concerns further intervention is not needed. The findings of the present study suggest that a professional's own level of comfort with the topic of sexuality may have more bearing on their abilities to engage with sexual issues than their particular professional training. When

Schmitz and Finkelstein (2010) interviewed stroke survivors about their sexual needs, they found that participants were aware of professionals' own discomfort and also believed that this made it difficult for them to speak about it to patients.

Limitations

The presented theory addresses a broad research question in order to generate meaningful clinical implications. However each higher-level category of the model could be the focus of further development, and the multiple categories may reduce the clarity of the model.

The sample was self-selected and this may have biased the sample towards individuals more comfortable speaking about sexuality. Despite efforts to help the participants to feel at ease, they may have found it difficult to express their views. Although the researcher aimed to take a neutral stance, the topic of the research may have led to participants assuming the researcher's position and perhaps feel their practice was being criticised or to feel they had to agree with a more liberal approach towards sexuality.

Participants were asked about experiences of sexuality coming up within their work, but for the majority of participants this was a rare occurrence. In the absence of experience, participants often gave predictions of how they would act in hypothetical situations. Although providing useful insights, it cannot be known how closely these predictions would match real behaviour. Triangulation (Urquhart, 2013) with patient data would develop the model further and highlight similarities and differences between patient and professional views. However, the opportunity to do this is limited while HCPs do not engage with patients on sexual issues.

The researcher did not seek to impose a definition of sexuality upon the participants and allowed them to consider the area in their own way. Participants tended to generate

clinical examples relating to sexual-functioning and not the broader aspects of sexuality.

Therefore the present theory may have more relevance to issues relating to sexual-functioning than other aspects of sexuality.

The research took an interpretivist position and it is possible that another researcher with different views and experiences might have interpreted the findings in a different manner.

Clinical Implications

The findings of this study support previous suggestions (Stein, Hillinger, Clancy & Bishop, 2013) that for the majority of patients, sexuality issues come up after hospital discharge and may be best addressed in the community. Patients may need time to understand the difficulties they are experiencing and develop the relationships with professionals necessary to addressing the concern, which may not suit the current typical timing of professional involvement. Addressing sexual concerns may require longer-term involvement and follow-up, to ensure that sexuality does not get “lost” whilst more “immediate” concerns are addressed.

Although the findings suggest that all professionals can take a role in the identification and support of patients who experience sexual difficulties post-stroke, clinical psychologists may be particularly well-placed to take up this role. Psychologists may be more likely to have longer-term contact with patients and therefore also have the opportunity to develop the kind of therapeutic relationships that facilitate the patient bringing up sensitive issues. Although many clinical psychologists will have received limited training in working with sexual issues (Shaw, Butler & Marriott, 2008), their general training in building rapport and facilitating communication with patients may also assist patients to bring sexual concerns to them. Although the study concerns stroke rehabilitation, these

factors may have relevance for psychologists working in other areas of rehabilitation and clinical health. However, as sexual issues may frequently be brought up within the context of non-psychological rehabilitation needs, it will be necessary for other professionals to also be prepared to respond to these concerns within their own work.

The present findings can be used to inform the development of interventions for professionals to help them to support patients experiencing sexual concerns. The PLISSIT model (Annon, 1971), which has been utilised in sexuality training in other settings (Simpson, Anway, Wilson & Bertapelle, 2006), is relevant to stroke rehabilitation. The participants who appeared most able to meet patients' needs did not view sexuality as a "specialist" area and were able to apply their own abilities to managing a sexual concern. Staff training could use this message to help HCPs to consider how they could transfer the skills they already have to working sexual issues. The skills clinical psychologists have in terms of working with teams and considering multiple perspectives could place them well to develop and deliver this type of training or more informal consultation. Participant responses suggested that psychologists are often seen as a point of call and referral for sexual issues. However, the positioning of the psychologist would have to be carefully considered, so that a message was not conveyed that sexual issues are the domain of clinical psychology only.

As participants frequently described difficulties "finding the words" to talk about sex, communication skills could be another focus of training. This has been picked up already in support for staff (e.g. The Sexual Respect Toolkit, Outsiders Trust, 2013). Motivational interviewing training developed for "dealing with difficult conversations", in stroke care, particularly around sexuality (Wright, Page, Hill & Pyle, 2013) showed increases in participant confidence around discussing sexuality.

Many participants reported that they found reflecting on their experiences and attitudes in the research interview helpful and it caused them to think about changing their practice. Incorporating reflective practice into training (such as reflective groups facilitated by clinical psychologists or other psychotherapy professionals) may assist professionals with getting in touch with the relevance of sexuality to their role and their patients. Training cannot change professionals' personality and background, but it has been suggested that it might be used to help individuals to separate their own position from the needs of their patients (Fronek, Kendall, Booth, Eugarde & Geraghty, 2011).

Although HCPS aimed to be open-minded and inclusive, the use of stereotypes in relation to age and gender was evident. Staff training might seek to explore these attitudes and encourage a more open-minded, inclusive approach.

Participants' practice was informed by local policy and procedures (such as standard assessment forms), and these did not include mention of sexuality. The development of a care pathway would support professionals in knowing how to address sexual issues.

Conclusion

This study constructed a theoretical model of how HCPs within stroke rehabilitation engage with the sexual concerns of their patients. Sexuality was often not considered within rehabilitation, but professionals adopted both direct and indirect approaches to approaching the topic with patients. Their own personal level of comfort interacted with a series of barriers to limit their ability to engage with and address their patients' concerns. These included organisational barriers, their perception of their own lack of skill and unhelpful attitudes towards patients and sexuality. The results reinforce the findings of previous research suggesting that the organisation does not work to legitimise the topic of

sexuality, and highlighted the importance of “permission-giving” and the use of generic communication skills in the support of patients. The findings suggest that training focusing on transferable skills and reflecting broadly on the role of sexuality within rehabilitation could serve to improve professionals’ confidence and efficacy with managing patients’ concerns.

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MAJOR RESEARCH PROJECT

ALEXANDRA F. RICHARDS

Section C: Appendices

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

SEPTEMBER 2014

SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY

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Appendix A: Search Methodology

The following electronic databases were searched: PsychINFO, Web of Science, MEDLINE, PubMed, ASSIA and Google Scholar. The searches took place between January and October 2013. The following search terms were used:

“sexuality/sexual function/”

OR

“intimacy”

OR

“spouse/partner”

AND

“stroke/cerebral haemorrhage/cerebral haemorrhage/acquired brain injury/hemiplegia/neurodisability”

Terms “sex”, “sexual” and “relationship” were not used due to being highly common words used in papers unrelated to sexuality/sexual functioning.

Inclusion/Exclusion Criteria

Papers relating to sexual consequences of a stroke were included if they were published between September 2003 and September 2013. Due to the low number of papers relating to sexuality within stroke rehabilitation, all papers were included regardless of date published.

Papers were required to concern stroke (either stroke survivors, partners of stroke survivors or staff working with stroke survivors). Papers that additionally involved other kinds of acquired brain injury or neurological condition were included, but only the aspects relevant to stroke are included in the review. Similarly, papers involving cardiovascular disease were studied and the aspects relevant to stroke are included in the review. Papers generated in the search that referred only to sex defined as the “category of male or female” were not included. Papers that referred only to incidence of stroke and not to experiences of stroke were not included.

Papers that referred only to familial relationships/roles rather than intimate relationships were excluded. Only papers in English were included.

Study Abstraction

Searches with pairs of key words (as outlined above) yielded over 300 items each. The titles of the first 100 items were read and those the abstracts of those that appeared to be related to the search were studied to assess whether their relevance and whether they met the inclusion criteria. This search yielded ten studies and two review papers.

References and citations of relevant papers were studied and papers published by key authors. This yielded a further 17 studies and seven review papers.

Appendix B: Overview of Included Studies and Documents**Impact of Stroke on Sexuality**

| Study (Country) | Aims | Sample | Design and Analysis | Measures | Main findings |
|---|--|--|--|---|--|
| Akinpelu, A. O., Osose, A. A., Odole, A. C., & Odunaiya, N. A. (2013). Sexual dysfunction in Nigerian stroke survivors. <i>African Health Sciences</i> , 13(3), 639-645. (Nigeria) | Reporting the prevalence of post-stroke sexual dysfunction in Nigerian stroke survivors | 77 stroke survivors attending a physiotherapy clinic | Quantitative study using questionnaire (adapted from Korpelainen et al.) | Own questionnaire, Beck Depression Inventory, Stroke Specific Quality of Life Scale, Modified Motor Assessment Scale. | Most (94.8%) participants reported a dysfunction in sexual function. Decline in libido and coital frequency were reported by >70% and in erection, ejaculation and orgasm by >60% of participants. Participants' with erectile dysfunction were significantly older than those without ($U=267.0$; $p=0.02$). Depression, quality of life, willingness to have sex, general attitude to sex and ability to express sexual feelings had significant influence on sexual dysfunction reported by participants ($p<0.05$). |
| Chambon, X. (2011). Testimony on the sexuality of post-stroke hemiplegic patients. <i>Sexologies</i> , 20(2), 102-105. (France) | To investigate the semiology of the sexual difficulties experienced by hemiplegic patients | 15 stroke survivors with hemiplegia | Quantitative study using questionnaire | Barthel Index, Beck Score, Hudson Sexual Satisfaction questionnaire | High medication intake was not found to be related to level of sexual difficulty or "sexual impairment". Due to the small sample size, it was not possible to find a correlation between quality of sexuality and level of independence. No relationship was found between level of depression, site of stroke and the level of sexuality difficulty. |
| Thompson, S., & Walker, L. (2011). Sexual dysfunction after stroke: underestimating the importance of psychological and physical issues. <i>Webmed Central</i> . | Reviewing the literature, makes recommendations for research and rehabilitation | N/A | N/A | N/A | Stresses the importance of both physical and psychological factors and recommends sexuality is included within rehabilitation. |

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| <p>Boosman, H., Schepers, V. P. M., Post, M. W. M., & Visser-Meily, J. M. A. (2011). Social activity contributes independently to life satisfaction three years post stroke. <i>Clinical rehabilitation</i>, 25(5), 460-467. (Netherlands)</p> | <p>To determine social activity and life satisfaction three years post stroke and to investigate the contribution of social activity to life satisfaction.</p> | <p>165 stroke survivors</p> | <p>Cross-sectional study</p> | <p>The Life Satisfaction questionnaire (LiSat-9), the Social Support List – Interaction (SSL-12-I), the Barthel Index, the Mini-Mental State Examination (MMSE) and the Frenchay Activities Index.</p> | <p>Lowest satisfaction ratings were found for sexual life (40.6%, $n = 58$)</p> |
| <p>Calabrò, R. S., Gervasi, G., & Bramanti, P. (2011). Male sexual disorders following stroke: an overview. <i>International Journal of Neuroscience</i>, 121(11), 598-604.</p> | <p>To evaluate the burden of stroke on sexual function taking into account the complex interaction between neurological, psychological, and relational factors.</p> | <p>N/A</p> | <p>Review</p> | <p>N/A</p> | <p>Male sexual disorders are common after stroke, especially for those who are older and have other pre-morbid conditions.</p> |
| <p>Schmitz, M. A., & Finkelstein, M. (2010). Perspectives on poststroke sexual issues and rehabilitation needs. <i>Topics in stroke rehabilitation</i>, 17(3), 204-213.</p> | <p>Described in rehabilitation table</p> | <p>-</p> | <p>-</p> | <p>-</p> | <p>-</p> |

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| Duits, A., Van Oirschot, N., Van Oostenbrugge, R. J., & Van Lankveld, J. (2009). The relevance of sexual responsiveness to sexual function in male stroke patients. <i>The journal of sexual medicine</i> , 6(12), 3320-3326. (Netherlands) | To investigate impact of mood and sexual responsiveness on sexual function | 19 male stroke survivors | Quantitative study, questionnaire | International Index of Erectile Function (IIEF), Symptom Checklist-90, the Sexual Inhibition/Sexual Excitation Scale | Sexual excitation was positively related to sexual desire, whereas inhibition because of the threat of performance failure was negatively related to orgasmic function and sexual desire ($P < 0.01$). Patients with high levels of inhibition because of threat of performance failure were more likely to report low scores on overall sexual function than those with low levels. |
| Thompson, H. S., & Ryan, A. (2009). The impact of stroke consequences on spousal relationships from the perspective of the person with stroke. <i>Journal of Clinical Nursing</i> , 18(12), 1803-1811. (UK) | To explore the experience of stroke recovery within spousal relationships | 16 stroke survivors. Mean age 56. | Qualitative, interview, content analysis | N/A | Post stroke, spousal relationships altered significantly in terms of sexuality, sexual desire and sexual functioning. Within their role of husband or wife, stroke survivors described a lack of control and dramatic changes in their perception of self. |
| Kautz, D. D., Van Horn, E. R., & Moore, C. (2009). Sex after stroke: an integrative review and recommendations for clinical practice. <i>Critical Reviews™ in Physical and Rehabilitation Medicine</i> , 21(2). | To summarize research from the prior 10 years about sex after stroke, including sexual function, sexual self-concept, and sexual relationships; make recommendations for future research; and provide clinical recommendations for practitioners caring for stroke | Seventeen international studies conducted in several disciplines from 1999 to 2009 | Review | N/A | After a stroke, some couples experience decreased sexual desire, decreased erections, vaginal dryness, and decreased frequency of sexual intercourse, as well as problems with masculine and feminine self-concept and with intimacy and sexual relationships with their partners. However, these studies also confirm that some couples do not experience these problems and some even experience a positive impact on sex and intimacy after stroke. Future research needs to focus on why some couples experience sex and intimacy gains, why some do not change, and why others experience losses. Future research also needs to test interventions by clinical practitioners to |

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| | survivors and their intimate partners. | | | | assist couples to overcome or compensate for changes in sex and intimacy after stroke. Potential interventions and resources for clinicians are included in this article. |
| Daniel, K., Wolfe, C. D., Busch, M. A., & McKeivitt, C. (2009). What are the social consequences of stroke for working-aged adults? A systematic review. <i>Stroke</i> , 40(6), e431-e440. | To identify the social consequences of stroke in working-aged adults. | 78 studies included | Review | N/A | Seventy studies reported data on return to work after stroke with proportions ranging from 0% to 100%. Other categories of social consequences included negative impact on family relationships (5% to 54%), deterioration in sexual life (5% to 76%), economic difficulties (24% to 33%), and deterioration in leisure activities (15% to 79%). |
| Visser-Meily, A., Post, M., van de Port, I., Maas, C., Forstberg-Wärleby, G., & Lindeman, E. (2009). Psychosocial functioning of spouses of patients with stroke from initial inpatient rehabilitation to 3 years poststroke course and relations with coping strategies. <i>Stroke</i> , 40(4), 1399-1404. (Netherlands) | Assessing the changes in the psychosocial functioning of spouses during the first 3 years after stroke and identifying predictors of the course of spouses' psychosocial functioning based on the characteristics of patients and spouses with special emphasis on coping style. | 67 spouses of first stroke patients, < age 75 | Quantitative, questionnaire | Life Satisfaction Checklist (LiSat-9). | Compared with their life before stroke, the spouses' satisfaction with life as a whole, their leisure situation, daily occupation, sexual life, partner relationship and social contacts was lower 4 months after stroke. Spouses of patients with sensorimotor impairment and low ability in self-care were less satisfied with their leisure situation, daily occupations, own ability in self-care, sexual life and partner relationship. Spouses of patients with cognitive or astheno-emotional impairments were less satisfied with their partner relationship, family life and sexual life. |

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| <p>Bener, A., Al-Hamaq, A. O., Kamran, S., & Al-Ansari, A. (2008). Prevalence of erectile dysfunction in male stroke patients, and associated co-morbidities and risk factors. <i>International urology and nephrology</i>, 40(3), 701-708. (Qatar)</p> | <p>To investigate the prevalence and severity of erectile dysfunction in stroke survivors and to assess co-morbidities and risk factors.</p> | <p>605 Quatari and non-Quatari stroke survivors</p> | <p>Quantitative questionnaire given through interview</p> | <p>International Index of Erectile Function (IIEF)</p> | <p>48% reported some degree of erectile dysfunction. Prevalence increased with age and the presence of hypercholesterolemia, diabetes, hypertension and medication taken for these diseases.</p> |
| <p>Kim, J. H., & Kim, O. (2008). Influence of mastery and sexual frequency on depression in Korean men after a stroke. <i>Journal of psychosomatic research</i>, 65(6), 565-569. (South Korea)</p> | <p>To investigate the influence of sexual frequency and the sense of control on depression in Korean men after stroke.</p> | <p>67 male stroke survivors</p> | <p>quantitative questionnaire</p> | <p>Sexual Frequency scale, the Mastery scale, and the Centre for Epidemiologic Studies Depression (CES-D) test.</p> | <p>Seventy-eight percent of the subjects were depressed. Sense of control and sexual frequency contributed to depression. Scores on sense of control and sexual frequency accounted for 39.5% of the variance in the depression score.</p> |
| <p>Tamam, Y., Tamam, L., Akil, E., Yasan, A., & Tamam, B. (2008). Post-stroke sexual functioning in first stroke patients. <i>European Journal of Neurology</i>, 15(7), 660-666. (Turkey)</p> | <p>To assess the impact of stroke on sexual functioning in a Turkish group</p> | <p>103 stroke survivors with mild or no disability</p> | <p>quantitative questionnaire</p> | <p>NIH Stroke, Glasgow Coma scale, Barthel and Rankin scales</p> | <p>There was a significant difference between the baseline and post-stroke frequency of sexual activity of the patients. The differences between baseline and post-stroke vaginal lubrication, orgasms and satisfaction were all statistically significant. Frequency of sexual activity both prior to and after the stroke was significantly different between males and females. Erection and ejaculation of the males was significantly affected by the stroke, and lubrication and orgasm was affected in the females.</p> |

APPENDICES

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| <p>Jung, J. H., Kam, S. C., Choi, S. M., Jae, S. U., Lee, S. H., & Hyun, J. S. (2008). Sexual dysfunction in male stroke patients: correlation between brain lesions and sexual function. <i>Urology</i>, 71(1), 99-103 (South Korea)</p> | <p>To identify sexual function and the impact of location of brain lesions</p> | <p>109 stroke survivors and 109 age-matched controls</p> | <p>Quantitative study, questionnaire</p> | <p>International Index of Erectile Function (IIEF)</p> | <p>Erectile function was significantly decreased in the stroke patient group compared with the control group. In most patients, the frequency of intercourse and sexual desire decreased after stroke, and an ejaculation disorder accompanied intercourse, but fear regarding intercourse was not severe. A lack of sexual desire was the largest cause (59.4%) of an absence of sexual intercourse. In cases with lesions in the right cerebellum and the left basal ganglia, a significant ejaculation disorder and decrease of sexual desire were more likely to occur, respectively.</p> |
| <p>Paraskevas, K. I., Bessias, N., Pavlidis, P., Maras, D., Papas, T. T., Gekas, C. D., & Andrikopoulos, V. (2008). Erectile dysfunction in stroke patients: a multifactorial problem with important psychosocial consequences. <i>International urology and nephrology</i>, 40(4), 1113-1114. (Greece)</p> | <p>N/A</p> | <p>N/A</p> | <p>Letter in response to Bener</p> | <p>N/A</p> | <p>Found similar findings, stressed considering psychosocial factors</p> |
| <p>Rees, P. M., Fowler, C. J., & Maas, C. P. (2007). Sexual function in men and women with neurological disorders. <i>The Lancet</i>, 369(9560), 512-525.</p> | <p>Reviews sexual functioning in neurological conditions, including stroke</p> | <p>N/A</p> | <p>N/A</p> | <p>N/A</p> | <p>Sexual dysfunction is common after stroke and appears to be more related to psychosocial factors than organic factors.</p> |

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| <p>Murray, C. D., & Harrison, B. (2004). The meaning and experience of being a stroke survivor: an interpretative phenomenological analysis. <i>Disability & Rehabilitation</i>, 26(13), 808-816. (UK)</p> | <p>Investigating the meaning and experience of being a stroke survivor</p> | <p>10 stroke survivors</p> | <p>Qualitative, IPA</p> | <p>Interviews</p> | <p>Four themes emerged from the analysis: Disrupted embodiment and the loss of self; Invisibility of emotional difficulties; Gender, romance and sexuality; and Social interaction. These themes, respectively, revealed that participants often had difficulties with psychological adaptation to the physically disabling aspects of their stroke; they experienced enduring and disabling emotional difficulties; they had a particular concern for the viability and maintenance of romantic and sexual relationships; and they often became socially withdrawn, resulting in an increased pressure on familial caregivers.</p> |
| <p>Banks, P., & Pearson, C. (2004). Parallel lives: younger stroke survivors and their partners coping with crisis. <i>Sexual and Relationship Therapy</i>, 19(4), 413-429. (UK)</p> | <p>Investigating the ways in which stroke had impacted SS and partner over year post-stroke</p> | <p>38 stroke survivors aged 20-49 and their partners</p> | <p>Qualitative, interview, after 3-6 months then after 6-9 months. Grounded theory.</p> | <p>N/A</p> | <p>12-15 months post-discharge from hospital, some participants spoke of altered roles, additional responsibility, changed relationships, and communication problems. However, few couples had been offered any form of counselling or psychological support. Changes in romantic and sexual relationships were often reported. Cognitive impairments particularly impacted negatively on sexual life and impacted on how the partner saw the SS. Understood their difficulties as relating to medication.</p> |

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| Giaquinto, S., Buzzelli, S., Di Francesco, L., & Nolfi, G. (2003). Evaluation of sexual changes after stroke. <i>The Journal of clinical psychiatry</i> , 64(3), 302-307. (Italy) | Investigating sexual functioning one year post-stroke | 68 stroke survivors | Quantitative study, questionnaire | Own questionnaire, Cumulative Illness Rating Scale, the Centre for Epidemiologic Studies-Depression scale, Structured Clinical Interview, Functional Independence Measure | Sexual decline was common in the post-stroke period. Age ($p = .009$) and disability ($p = .0059$) were significant variables. There was no correlation between sexual decline and gender, nor injured hemisphere. There was also no correlation to marriage duration, education duration, or depression. Evaluation and analysis of the questionnaires revealed, however, that patients' partners played a substantial role in the decline of sexual activity. Many partners experienced fear of relapse, anguish, lack of excitement, or even horror, which withheld them from encouraging sexual activities. |
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Sexuality within Stroke Rehabilitation

| Study (Country) | Aims | Sample | Design and Analysis | Measures | Main findings |
|--|---|---|---|---|--|
| McCluskey, A., Vratsistas-Curto, A., & Schurr, K. (2013). Barriers and enablers to implementing multiple stroke guideline recommendations: a qualitative study. <i>BMC health services research</i> , 13(1), 1-13. (Australia) | To identify barriers and enablers to implementing stroke guidelines at a stroke unit. | 28 health professionals at a stroke unit. | Qualitative study using thematic analysis | Group and individual semi-structured interviews | Key barriers identified: Beliefs about capabilities of both professionals and patients, beliefs about consequences of implementing recommendations, memory and attention to best practices, knowledge and skills required to implement best practices, intention and motivation to implement and resources available. Sexuality was an area in which there was particular resistance to changing practice to adhere to guidelines. |

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| Hall, J. (2013). Sexuality and stroke: the effects and holistic management. <i>British Journal of Nursing</i> , 22(10), 556-559. | Review of post-stroke sexuality literature and implications for nursing care | N/A | Review | N/A | References PLISSIT Model |
| Stein, J., Hillinger, M., Clancy, C., & Bishop, L. (2013). Sexuality after stroke: patient counseling preferences. <i>Disability & Rehabilitation</i> , 35(21), 1842-1847. (USA) | To investigate stroke survivors' preferences for sexuality-related counselling | 38 Stroke survivors | Quantitative and qualitative study | Changes in Sexual Functioning Questionnaire Short Form (CSFQ-14) Fatigue Assessment Scale (FAS) Beck Depression Inventory Self-report Barthel Index and own questionnaire | Sexual dysfunction was common (47%) and 71% of participants regarded sexuality a moderately to very important part of stroke rehabilitation. 60% indicated a preference for receiving sexuality-related counselling from a doctor. 26.5% wanted to receive counselling prior to hospital discharge, and 71% wished to receive it within a year post-stroke. 81% had received insufficient information during their rehabilitation |
| Mores, G., Whiteman, R., Knobl, P., Ploeg, J., Cahn, M., Klaponski, L., & Lindley, A. (2012). Pilot evaluation of the family informal caregiver stroke self-management program. <i>Canadian Journal of Neuroscience Nursing</i> , 35(2), 18-26. (Canada) | To evaluate a Family Informal Caregiver Stroke Self-management program (which included sexuality and intimacy and a module) | 11 family caregivers (10 spouses) of stroke survivors with a mean 3 years of caregiving experience | Qualitative and quantitative pilot study | Semi-structured focus group The Caregiver & Stroke Survivor Baseline Questionnaire The Oberst Caregiving Burden Scale | Participants valued the group and the opportunity to learn and share experiences. They made recommendations for improving the group, including removing the topic of sexuality and replacing it with topics seen as more important such as grief. |

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| Hamam, N., McCluskey, A., & Cooper Robbins, S. (2012). Sex after stroke: a content analysis of printable educational materials available online. <i>International Journal of Stroke</i> , 8(7), 518-528. | To identify, describe and analyse educational materials on post-stroke sexual concerns that are easily available to stroke survivors | 9 educational materials | Qualitative using content analysis | N/A | Materials reviewed described post-stroke sexual consequences in line with the available literature but recommendations and solutions were often general, non-specific and not supported by research evidence. |
| Song, H., Oh, H., Kim, H., & Seo, W. (2011). Effects of a sexual rehabilitation intervention program on stroke patients and their spouses. <i>Neurorehabilitation</i> , 28(2), 143-150. (South Korea) | To investigate the efficacy of a sexual rehabilitation intervention program | 12 couples where one member was a stroke survivor, and a control group of 11 couples. | Quantitative study | Sexual Beliefs and Information Questionnaire Derogatis Sexual Functioning Inventory (DSFI) Adapted McCabe and Telporos Sexual Frequency scale Mini-Mental State Examination Barthel Index | The treatment group showed significantly increased sexual satisfaction and frequency of sexual activity. Sexual knowledge was not increased. |
| Hamam, N. (2011). Sex, drugs and the medical role: A case report of a man prescribed Alprazolam following stroke. <i>The Australasian medical journal</i> , 4(11), 608. (Australia) | Describing the case of a male stroke survivor with post-stroke sexual dysfunction, this was resolved following a medication | 64 year old man 5 years post-stroke | Case study | N/A | The sexual dysfunction only came to light following the man's involvement in research. Following recommendation from the researcher, he visited his GP and a medication change entirely resolved the sexual difficulties he had been experiencing. |

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| | review. | | | | |
| Hafsteinsdóttir, T. B., Vergunst, M., Lindeman, E., & Schuurmans, M. (2011). Educational needs of patients with a stroke and their caregivers: a systematic review of the literature. <i>Patient education and counseling</i> , 85(1), 14-25. | To systematically review the research on stroke patients' and caregivers' educational needs. | N/A | Systematic review | N/A | Sexuality was an important issue to patients and caregivers and education was wanted. |
| Schmitz, M. A., & Finkelstein, M. (2010). Perspectives on poststroke sexual issues and rehabilitation needs. <i>Topics in stroke rehabilitation</i> , 17(3), 204-213. (USA) | To investigate the perspectives and experiences of stroke survivors and their partners regarding sexuality and their perceived rehabilitation needs | 15 stroke survivors and 14 partners of stroke survivors | Qualitative study using thematic analysis | Semi-structured interviews | 2 themes identified related to effect of stroke on sexual life: physical changes and relationship changes. 5 themes related to rehabilitation: Difficulty in patients and professionals talking about sex, little or no discussion of sexuality post-stroke, need for education tailored to individual needs, professional rapport and competence and the timing of post-stroke sexual education |

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|--|---|---|---------------------------|---|---|
| <p>Conrad, N., Doering, B. K., Rief, W., & Exner, C. (2010). Looking beyond the importance of life goals. The personal goal model of subjective well-being in neuropsychological rehabilitation. <i>Clinical rehabilitation</i>, 24(5), 431-443. (Germany)</p> | <p>To identify the subjective importance, attainability and success of life goals and their predictive value for well-being in patients with acquired brain injury.</p> | <p>59 individuals with acquired brain injury (52 stroke) recruited from 2 neurological rehabilitation centres</p> | <p>Quantitative study</p> | <p>Life Goals Questionnaire (GOALS) Centre for Epidemiological Studies Depression Scale (CES-D) Satisfaction With Life Scale (SWLS) The Positive and Negative Affect Schedule (PANAS)</p> | <p>Intimacy was found to be the most important and most attainable life-goal</p> |
| <p>Shah, M., (2009). Sexuality after stroke. In Stein, J., Harvey, L. R., Macko, F. R., Winstein, J.C., & Zorowitz, D. R. (Eds.), <i>Stroke, Recovery & Rehabilitation</i> (pp.721-734). New York: Demos Medical Publishing.</p> | <p>Review of sexuality post-stroke and implications for rehabilitation</p> | <p>N/A</p> | <p>Book chapter</p> | <p>N/A</p> | <p>References PLISSIT Model</p> |
| <p>Kautz, D. D. (2007). Hope for love: practical advice for intimacy and sex after stroke. <i>Rehabilitation Nursing</i>, 32(3), 95-103.</p> | <p>Reviews the literature on post-stroke sexual difficulties and makes suggestions for nursing professionals</p> | <p>N/A</p> | <p>Review</p> | <p>N/A</p> | <p>References PLISSIT model and tools nurses can use to address sexual issues</p> |

| | | | | | |
|---|---|---|--|--|--|
| <p>Choi-Kwon, S., Lee, S. K., Park, H. A., Kwon, S. U., Ahn, J. S., & Kim, J. S. (2005). What stroke patients want to know and what medical professionals think they should know about stroke: Korean perspectives. <i>Patient education and counseling</i>, 56(1), 85-92. (South Korea)</p> | <p>Comparing the education needs of stroke survivors and professionals views</p> | <p>50 stroke survivors, 88 medical professionals</p> | <p>Quantitative study, questionnaire</p> | <p>“a structured questionnaire regarding various aspects of patient education concerning stroke”</p> | <p>Highlights that patients want education regarding sexuality. Younger patients gave higher rankings than older patients for items concerning ‘medical knowledge regarding stroke,’ ‘exercise,’ and ‘post-stroke sexual activities’ (P<0.01 for each).</p> |
| <p>McLaughlin, J., & Cregan, A. (2005). Sexuality in stroke care: a neglected quality of life issue in stroke rehabilitation? A pilot study. <i>Sexuality and Disability</i>, 23(4), 213-226. (Ireland)</p> | <p>Exploring 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.</p> | <p>16 health professionals from community and hospital based stroke services</p> | <p>Quantitative questionnaire</p> | <p>Own questionnaire</p> | <p>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.</p> |
| <p>Greenberg, E., Treger, J., & Ring, H. (2004). Post-stroke follow-up in a rehabilitation center outpatient clinic. <i>The Israel Medical Association journal: IMAJ</i>, 6(10), 603-606. (Israel)</p> | <p>To review patient complaints at follow-up and the recommendations issued at the outpatient clinic.</p> | <p>120 patients discharged from the rehabilitation facility over a 2 year period.</p> | <p>Audit</p> | <p>Functional status (FIM) on admission and discharge, length of stay, and number of complaints. Clinical details collected.</p> | <p>3% complained of sexual dysfunction, sexual rehabilitation was recommended for 10%</p> |

| | | | | | |
|---|--|--|-------------------------------------|--|---|
| <p>Chadwick, L., Saver, J., Biller, J., & Carr, J. (1998). Stroke and quality of life: intimacy and sexuality poststroke. <i>Loss, Grief & Care</i>, 8(1-2), 63-69. (USA)</p> | <p>Investigating the resumption of post-stroke sexual activity/intimacy and its importance to stroke patients and their sexual partners.</p> | <p>27 stroke survivors and 19 partners Twenty-seven patients responded</p> | <p>Mixed methods, questionnaire</p> | <p>A basic data demographic form, individual patient and partner questionnaires, and the Beck Depression Inventory</p> | <p>Ten patients had not resumed sexual activity. Seventeen patients had re-established a sexual relationship. Both patients and partners, stated post-stroke sexual education was not received. This lack of sexual education warrants further investigation.</p> |
| <p>McCormick, G. P., Riffer, D. J., & Thompson, M. M. (1986). Coital positioning for stroke afflicted couples. <i>Rehabilitation Nursing</i>, 11(2), 17-19. (USA)</p> | <p>Reports the findings from a support group discussion.</p> | <p>37 spouses who took part in a support group</p> | <p>Qualitative</p> | <p>N/A</p> | <p>The group discussed the lack of health education, performance fears, aspects of sexual conditioning, acceptance of change, and options for coital positioning. None of the participants had received any education from rehabilitation professionals regarding post-stroke sexual activity</p> |

Appendix C: Participant Demographics

| P | Age Range | Gender | Profession | Work Setting | Length of experience working with stroke survivors |
|----------|------------------|---------------|--------------------------|-------------------------|---|
| 1 | 30-40 | F | Rehabilitation Assistant | Community | 2-4 years |
| 2 | 40-50 | F | Nurse | Community | 2-4 years |
| 3 | 30-40 | F | Clinical Psychologist | Inpatient and Community | 4-6 years |
| 4 | 40-50 | F | Physiotherapist | Community | <20 years |
| 5 | 40-50 | F | Occupational Therapist | Community | 6-8 years |
| 6 | 30-40 | F | Clinical Psychologist | Inpatient and Community | 2-4 years |
| 7 | 30-40 | F | Occupational Therapist | Community | 6-8 years |
| 8 | 50-60 | F | Occupational Therapist | Community | 6-8 years |
| 9 | 40-50 | F | Rehabilitation Assistant | Community | 2-4 years |
| 10 | 40-50 | F | Nurse | Inpatient | 14-16 years |

Profession - Some participants held dual roles (such as within management). This information is omitted to respect confidentiality.

Work setting - "Inpatient" refers to staff working on acute and rehabilitation stroke wards. "Community" refers to staff working in community-based services such as community neuro-rehabilitation teams.

Length of experience - Participants were asked to indicate to the nearest year the length of contact they had had with stroke survivors within a work capacity. Participants were able to define this in their own way.

Appendix 4: Ethics Approval

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Appendix 5: NHS Trust Research and Development Approval

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Appendix F: Participant Information Sheet**Information about the research for participants****Staff attitudes and beliefs about sexuality within stroke rehabilitation**

My name is Alexandra Richards and I am a Trainee Clinical Psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study, which I am carrying out as part of my doctorate in Clinical Psychology. The study is being supervised by Dr Rachel Dean (Senior Clinical Psychologist at Sevenoaks Hospital) and Dr Jerry Burgess (Senior Clinical and Academic Tutor at Canterbury Christ Church University) Before you decide it is important that you understand why the research is being done and what it would involve for you.

What is the purpose of the study?

Sexuality is often an overlooked area within stroke rehabilitation, despite evidence that following a stroke difficulties relating to sex and intimacy are common. This study aims to explore how staff think about sexuality in relation to their role working with individuals who have had a stroke, and the possible obstacles to approaching this topic within the rehabilitation setting.

Why have I been invited?

You have been invited because you are a professional working with individuals who have had a stroke. I am interested in the views of the different disciplines who work within stroke care. Staff will differ in how much contact they may have with patients who experience sexual difficulties, it is not important if you have not had much contact with these types of problem, I am still interested in your views.

Do I have to take part?

No, it is up to you to decide to join the study. If you agree to take part, I will ask you to sign a consent form (a copy is included here). You are free to withdraw at any time, and do not have to give a reason.

What will happen to me if I take part?

We will arrange a convenient time to complete an interview at your workplace or the interview can be completed over the telephone. The interview is not likely to take more than an hour and it will be recorded.

In the interview I will ask you some specific questions about how sexuality comes in to your work with stroke patients, but also some more general questions about your views about sexuality in relation to stroke rehabilitation.

What are the possible disadvantages and risks of taking part?

Sexuality can be a sensitive topic and you might find some of the questions difficult or uncomfortable to answer. There is no requirement to disclose any personal experiences in relation to sexuality; the discussion will be more concerned with your work. If during the interview you feel uncomfortable you can ask to stop and remove your data without having to give reasons.

Efforts will be made to make you feel at ease and comfortable during the interview. However, if the interview brings up some difficult feelings and you would like to

speak to someone about this, I can provide you with information on how to seek support. You could seek support from the following sources:

- The Occupational Health department within your trust
- Your GP
- NHS-funded counselling/talking therapy services. Details for these can be found through your GP or at these websites :

Kent- <http://www.kmpt.nhs.uk/pcpts>

Croydon - <http://www.slam-iapt.nhs.uk>

Tower Hamlets - <http://www.compassth.nhs.uk/>

- Samaritans – A national helpline you can speak to at any time if you are feeling distressed. They can be contacted on 08457 90 90 90, please see their website for further information
<http://www.samaritans.org/>

What are the possible benefits of taking part?

The research will be used to inform training interventions with staff, so your responses may contribute to improved provision of training for staff and subsequent benefits for patients. The interview might also provide a useful space to reflect on your practice and possible areas you wish to develop on.

What will happen if I don't want to carry on with the study?

If you decide at any point that you do not want to carry on being involved with the study, you may withdraw without having to give your reasons. Any data that has been collected about you can be removed and your interview will be deleted. It is your choice as to whether you continue to take part and how your information is used.

What if there is a problem?

Every effort will be made to ensure that the interview is conducted in a sensitive and respectful manner. However, if you have any concerns or complaints about the interview process, these will be taken extremely seriously and we will aim to address this immediately.

If you have a concern about any aspect of this study, please contact me on xxxx or Dr. Rachel Dean on xxx . If you remain unhappy and wish to complain formally, you can do this by speaking to Prof. Paul Camic, the Research Co-ordinator overseeing the project at the Department of Applied Psychology at Canterbury Christ Church on 0333 011 7070.

If at any point during the interview, you wish to stop or take a break, this will be possible and you can decide to have your information removed from the study if you wish.

Will my taking part in this study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. All information which is collected about you during the course

of the research will be kept strictly confidential, and any information about you which leaves the centre will have your name, date of birth and contact details removed and replaced with a code so that you cannot be recognised. I will be the only person who has direct access to these details. The interview will be transcribed, and following this the recording of the interview will be destroyed. The transcript will be kept by the university for 10 years, and then destroyed.

The only exception to this would be if you were to make a disclosure about staff misconduct. Depending on the nature of the disclosure, it might be necessary to pass on information to the manager of the team you work within. This would be discussed with you prior to sharing any information.

When the research is written up, anonymised quotations from the interview may be used. You can give consent to this on the consent sheet. If you wish for certain parts of your interview to not be included in quotations or to not be quoted at all, you can say so.

What will happen to the results of the research study?

The results of the study will be submitted as part of my doctoral thesis and we intend to publish the results in a scientific journal.

A summary of the results will be made available to the staff team and I shall be sending a copy to participants who are interested in seeing the results.

If you have given consent, some anonymised quotations from your interview may be included in the publication but you will not be identified personally.

Who is organising and funding the research?

Canterbury Christ Church University.

Who has reviewed the study?

The study has been reviewed by Canterbury Christ Church University and the Research and Development department within your NHS trust, who have approved it.

I want to take part but I would like some more information

Please contact me on xxx or at ar316@canterbury.ac.uk. I am happy to provide further details about the study and to answer any questions you have.

I am happy to take part

Please contact me on .xx or at ar316@canterbury.ac.uk. I will then get in touch to arrange with you a convenient time when I could meet you at your workplace or telephone to carry out the interview.

Appendix G: Consent Form

Centre Number:

Participant Identification Number for this study:

CONSENT FORM

Title of Project: Healthcare professionals' attitudes and beliefs about sexuality within stroke rehabilitation

Name of Researcher: Alexandra Richards

Please initial box

| | |
|--|--|
| 1. I confirm that I have read and understand the information sheet dated 31/08/2013 (version 4) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | |
|--|--|

| | |
|--|--|
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. | |
|--|--|

| | |
|---|--|
| 3. I agree to the audio-recording of my interview | |
|---|--|

| | |
|---|--|
| 4. I agree that anonymous quotes from my interview may be used in published reports of the study findings | |
|---|--|

| | |
|---|--|
| 6. I agree to take part in the above study. | |
|---|--|

Name of Participant _____ Date _____

Signature _____

Name of Person taking consent _____ Date _____

Signature _____

Appendix H: Demographics Form

Centre Number:

Participant Identification Number for this study:

Participant Demographics

Name:.....

Date of Birth:

Job Title:.....

Length of time working within Stroke Rehabilitation (within current post and any previous experience):

.....

If you are interested in receiving a summary of the results of this study, please leave a contact email or postal address:

.....

.....

.....

Appendix I: Initial interview Guide

(before recording)

How do you feel about doing the interview? Is it a difficult conversation?

(recording)

What is your role within the stroke team?

How long have you worked within stroke rehabilitation/with people who have experienced a stroke?

**What did you expect when you started working in stroke services?
Are sexual issues something you thought about?**

Do issues relating to sex and sexuality come up within your work?

- **Why do you think they come up?** I'm interested in your understanding of why issues relating to sexuality occur for people who have had a stroke
- **How do these issues come up?**

Tell me what it's been like when sex has come up in the work?

Potential follow-up questions: Has it come up in other ways (such as in a service user's behaviour towards you, or in discussion with other staff). How often? Why do you think it doesn't come up?

What did you think? How did you feel? What did you do? Did you feel prepared? Did characteristics of the individual make a difference? What would have helped?

Has there been anything in place in your service to help with these conversations?

Potential follow-up questions: Have you ever received training on how to address sexual concerns with patients? Do you think you would want to attend training on this? If yes, what would you want to get out of it?

Do you think feel that addressing sexuality issues should be part of your professional remit?

Do you think professionals of other disciplines should address the issue of sexuality with patients?

What do you think your discipline can particularly offer patients who are experiencing sexual problems following a stroke?

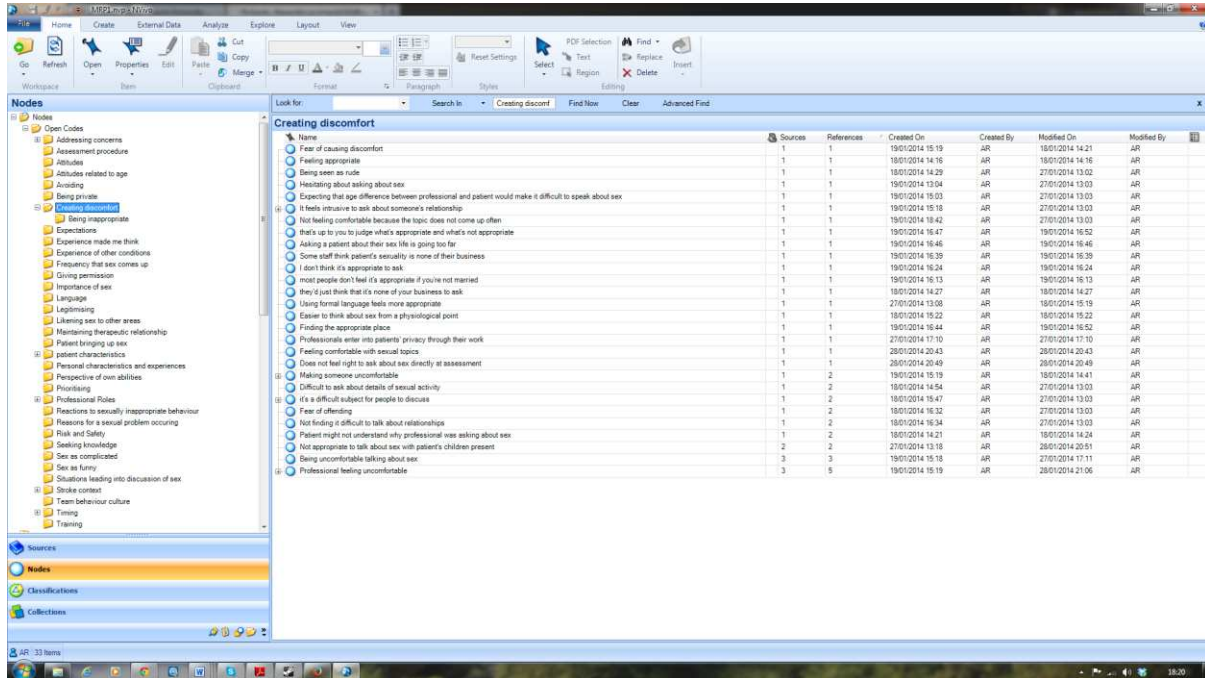
End – How was it having this conversation?

Appendix J – Coded Transcript

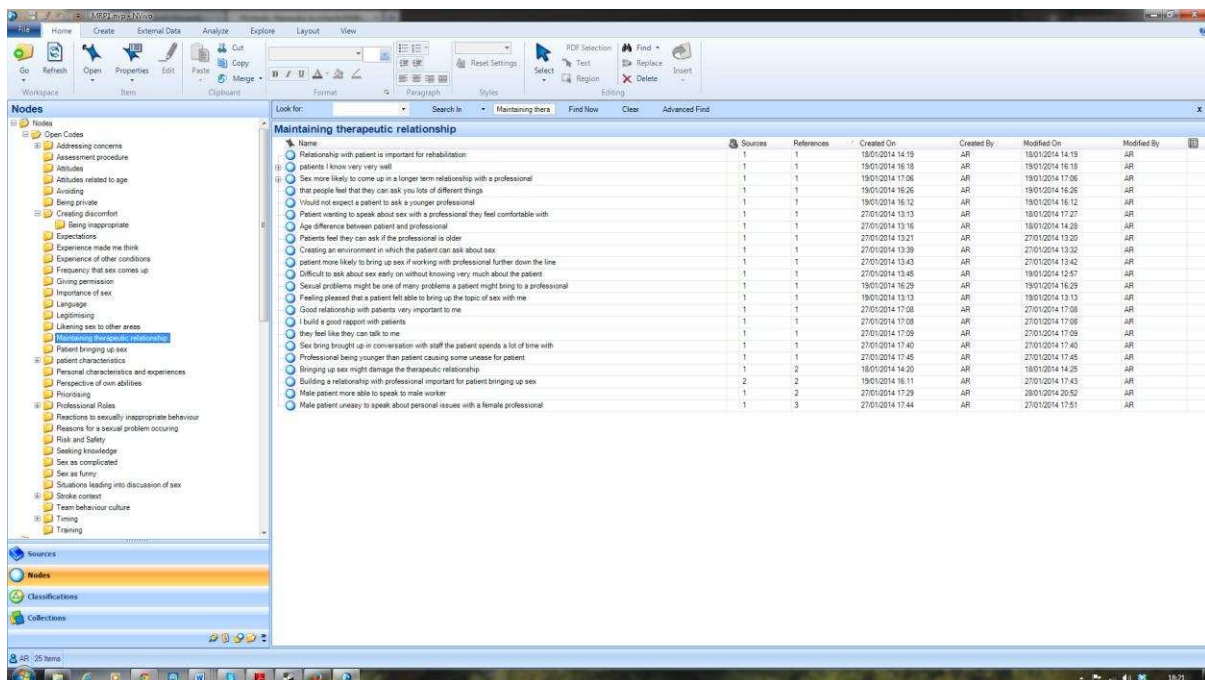
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Appendix K: Open Coding

Early screen-shots from Nvivo 9 of the process of open-coding, before codes were merged and developed into analytic, directional codes.



Experimentation with grouping of open-codes occurred, hence many open codes are listed under the folders on the left.



Appendix L: Developed Interview Guide

Ask if participant appears uneasy to build rapport, otherwise move into more focused questions:

(before recording)

How do you feel about doing the interview? Is it a difficult conversation?

(recording)

What is your role within the stroke team?

How long have you worked within stroke rehabilitation/with people who have experienced a stroke?

Do issues relating to sex and sexuality come up within your work?

- **How do these issues come up?**

Tell me what it's been like when sex has come up in the work?

(follow up questions as before)

Has there been anything in place in your service to help with these conversations?

Do you think feel that addressing sexuality issues should be part of your professional remit?

Do you think professionals of other disciplines should address the issue of sexuality with patients?

What do you think your discipline can particularly offer patients who are experiencing sexual problems following a stroke?

Additional questions:

Language – Would your language/the words you use be something you would think about when speaking about sexuality with a patient?

Timing – What time in someone's care pathway have these issues tended to come up?

When do you think they would come up? When do you think is the best time for a professional to bring them up?

Pathway – What do you/would you do if a patient brought up a sexual concern? Is there a pathway in place in your service?

Use of other professionals – If you needed help where would you go for it? Is there another professional or service? Would you use the GP as a source of support/information?

Similarity – Do you think it makes a difference when you and the patient are a similar age/same gender/ethnicity? Has that impacted on these encounters?

End – How was it having this conversation?

Appendix M – Extracts from Research Diary

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Appendix N - Memos on Emerging Categories

Impact of Personal Experiences on Professionals' Level of Comfort with Sex

"Um... yeah I think so I think so probably never had to discuss that with anyone and never been... what.... Perhaps not done sort of the things I've done in my life that you think "Well I've seen all that anyway" so just talking about sex compared to... changing someone's stoma is... you know it's not gonna gonna bother me"

"it's perhaps your own.. Experience as well in that... do I talk about sexuality and erm sex-lives with my friends no I don't so (laughs)"

Participants imply that their own personal experiences/life experience has contributed to their level of comfort with the topic of sex. This could be in terms of "I've seen a lot" and this changing their perspective. This could also be a career's worth of work-related experiences. They also consider that other professionals may not have had these experiences so have a different perspective.

I did not press people to discuss what life experiences had impacted on their level of comfort, though one participant did give examples (e.g. doing very intimate care with patients, seeing people who were in a very bad way, experiencing very negative life events and losses), so can only guess. Upbringing alluded to, and the culture people live in.

Can I ask people about this? Or is that going too far/offensive (interesting parallel process!)

Professionals' Own Personality Determines How Comfortable They Are Talking About Sex/Not Being Comfortable Talking About Sex Openly in Personal Life

"I think it actually comes down to personality some people are not comfortable talking about sex..."

“We’re all different as clinicians different I don’t think it’s necessarily the different professions maybe different characters

Level of comfort about sex/talking about sex seen as related to an individual’s personality (and personality related to life experiences, culture and upbringing). A sense here that personality (and therefore comfort level) is set, something that may not be changed or impacted on by training.

Personality considered in terms of level of comfort/discomfort, “openness” or being approachable, the kind of person appears to be able to talk about a range of topics (including more difficult ones). More/less conservative.

This seems to be about the impression you give off, outward perception of the person, if people see them as someone who is comfortable/open or not. Participants gave examples of observing how other staff members talk and this giving an idea of their attitude and personality. However, the attitude/personality someone gives off at work might be different from how they are in their personal life.

Participants relate their own and other professionals’ level of comfort with talking about sex with patients/at work to how openly they talk about sex in their personal life. An idea of “I wouldn’t want to share it myself, so I wouldn’t make someone else share it” Is there an assumption that others will share their discomfort? Does this consider others who may be more comfortable than them?

Meeting Patients Early in Their Rehabilitation

The majority of participants work in the community team, though some are involved at acute. Tending to see people just after they have been discharged from hospital. Sense that rehab is a long journey, and the team are involved at the early part, transition from hospital

to life in the community. Sense that there is a later (perhaps longer) part of rehab that professionals are not (as) involved with

Fearing that Sex Will Bring on Another Stroke

Not sure that this is a useful code, it doesn't tell a lot other than that this is a factor that comes up, not really a process

Staff were aware that patients had this fear, and that this could cause sexual problems/avoiding sexual activity. Questions posed to staff often related to this risk, such as blood pressure. Some staff also were not sure about the risks related to sex and were concerned that this was true and patients might be at risk, not confident to reassure patients that there is not a risk.

Sexual Issues Come Up Much Later Down the Line

"Maybe six down six months down the line they probably realise actually well we never really quite got back to the same married life we had, you know, prior to the stroke"

"if it comes up by the time it comes up for most people they've actually been discharged from most of the teams"

View that patients become aware of sexual issues later on in their rehab journey, usually after they have returned home and been there for a little while (at least a few months post-discharge). Idea that sex is not a concern to patients when they are in hospital (when they are in shock and they have other more immediate concerns), and these issues might be noticed later, once other things have "settled down".

Unclear if issues actually occur later, are only noticed later, it takes until later for the patient to be able to bring the issue up, needs to be in a longer relationship with services. As the

issues don't come up often hard for professionals to state, this is often a guess.

Cannot reflect patients who have a sexual concern but do not raise it, we do not know when this occurred or when it "should" be addressed, as it has not been brought up. Issues might come up after the individual has been discharged.

Is this a get-out – issues don't come up within the time-scale professionals are involved, so they don't have to ask. Does this highlight a gap in service provision for more long-term follow up, that some issues might come up then.

There are More Immediate Rehabilitation Priorities than Sex

"they've had a major life-changing event and really it's about making sure that they're going to get out of hospital rather than... thinking about the sexual kind of things"

if you've got a stroke and you can't walk, eat or drink yourself your sex life is something that...

Is something that's distant"

"They might not even be (emphasis) thinking at that level about sex intimacy as we said before they might be more worried about "I just want to be able to answer my front doorbell I just want to get to the toilet I just want to have a bath" that that's their priority "

Priorities for professionals and for patients. However, some patients have shown that sex is an early priority to them, but this does not fit with what professionals think should be a priority.

Early priorities include stabilising health and getting over shock of having had a stroke, then what is needed to be discharged from hospital.

Being able to move, be independent (transfers, eating, looking after self). These need to be dealt with before sex. This may be appropriate to prioritise these needs, but what priority is

sex and when should it be a priority? Focus on goals/tasks and ability.

Does this reflect organisational pressures? E.g. hospitals expensive, targets associated with discharge? Where do these less obvious areas fall, that are not strictly related to independence, but contribute to quality of life. Can it be a standard priority if there is no procedure?

Assuming that Sex is More Important to Younger People than Older People/ Generational Differences in Openness About Sex

“because I work with a lot of older people... where there’s that assumption that it’s not as important anymore”

“I know it’s a real stereotype but you can imagine perhaps a younger man who’s just had a stroke being that being something really quite at the forefront”

“Because it’s not something that that generation amongst themselves or whatever would generally talk about sex with the younger patients it comes up more “

Sometimes staff made direct references to using stereotypes about younger and older people and how important sex would be to them. Often they were aware that they were using a stereotype, some reporting that they should not do so, yet this still appeared to be impacting on their practice.

Staff often referring to sex in relation to younger patients, as though it would definitely be more of a concern to them.

Working with an older population appears to increase the hesitancy in staff to approach the topic of sexuality

Generational differences in openness/how people talk about sex are often stated as a fact (though rarely qualified with examples). Older generations do not talk openly about sex, it is

not seen as appropriate, sex is seen as something for when you are married. In younger people these “rules” do not apply and there is more openness.

Is this being used as an excuse to explain professional’s own discomfort, or is this appropriate sensitivity to cultural differences and patient’s own comfort?

Thinking About Sex in Relation to Other Intimate Areas

Participants reflect that although sex is an intimate issue, they already ask about other intimate issues (continence/bowels/toileting). Sometimes the topic comes up through discussion of these intimate areas. Nurses are seen as being involved in intimate/personal areas, which is used to explain why sex might come under their role.

Thinking About Sex in Relation to Activity and Movement

Particularly in relation to physios and OTs, thinking about sex in the context of stroke rehab , thinking of sex in terms of movement and activity (activities of daily living). This may be more in line with their profession and the knowledge they possess (transferring knowledge?) but may neglect other aspects of sexuality that are less “functional” or visible. Is this an easier or more comfortable way for professionals to think or talk about sex? Is it more legitimised through these topics, seems more acceptable. Would patients see it this way also?

Identifying Sexual Issues Should be the Responsibility of Everyone in the Team

“everyone’s responsibility really to just inquire”

Of note here is the term “**should**”. All participants agreed that sexual issues could come under their role, and they frequently mentioned other professionals whose role it would

come under also. Agreeing that sex should come under your role is not the same as actually dealing with it in your role or being comfortable or prepared to do so. But there seemed to be a general agreement that it was a part of the work.

Consideration that there can be a variety of different sexual concerns, some of which would fit more with one professional and their area of knowledge than another. Issues to do with “the mechanics” and functioning of body parts (e.g. erectile dysfunction) tended to be more associated with doctors and nurses. They were seen as areas requiring medical knowledge and possibly a medical intervention.

Issues relating to changes in relationships/roles, intimacy, feelings of being sexual and attractive, were seen as issues that might be appropriate to be dealt with by a psychologist or nurse, especially if counselling type interventions were needed.

OTs cover a mixed area, where they might be involved in goal-setting in relation to sex, “problem-solving” sexual difficulties, sexual difficulties related to movement and that might need adaptations

Everyone could have a role in identifying a concern, listening to the patient if they bring up an issue. Addressing a concern was however not seen as the remit of all professionals, with professionals varying in what they thought they could actually provide. Consideration that what may be most important is that the professional has a good relationship with the patient and that the patient feels comfortable to talk to them about sex. This might vary a lot and this professional might not be one typically associated with sexual issues or have much experience in it (e.g. a physio doing longer-term movement based work, or a rehab assistant) but it would be appropriate for them to be open to discussing the concerns and to listen to the patient.

Sex as an Important Issue

Sex as an important part of (someone's life), sex being shown to be important to the patient, sexual issues as important issues to be addressed and a part of rehabilitation.

Included data related to the centrality to sex in life and how it can be held as very important (although this varies amongst people).

Not a very useful code, but positive that it has come up

Sex as Very Personal and Private

Used as an explanation for why people (patients) might not want to talk about sexual issues.

Does not fit entirely with other "personal" areas that are covered by professionals, such as bowels and continence. Also seeing patient in their own home/bedroom. Certain "private" areas seem to be considered ok for professionals to step into, others not so. Why is this personal area seen as off bounds? And what makes other "personal" areas easier to approach? How do professionals manage when discussing these areas?

Not a very useful code

Fear of Causing Discomfort in the Patient by Asking About Sex

I feel like "Am I going to offend you by... talking about this?"

"you could offend some people actually"

Professionals want to avoid making the patient feel uncomfortable/awkward/thinking that the professional is being rude. This fear in itself seems to cause discomfort in the professional, even if they feel reasonably comfortable with the topic. The prospect of this potential negative outcome is uncomfortable.

Possibly this is related to the fear that bringing up the topic will damage/jeopardise the

therapeutic relationship with the patient.

Assumption that the patient will be made uncomfortable, rarely qualified with examples of when this has actually been the case. May relate to general perception of the general public as uncomfortable discussing sex.

Sex Being Brought up with Staff the Patient has a Closer Longer Term Relationship With

Professionals tend to have experienced patients as bringing up a sexual issue with them if they know them better, i.e. through a longer therapeutic relationship, a good quality of relationship, or assuming that this would have to be the case

Some professions might be more likely to have longer-term involvement (e.g. psychology), or certain patients (more complex, less social support)

What is it about the professional and the relationship that creates this acceptable environment for the patient to bring up the topic? Is it about the professional's personality/attitude they give off? Is it about some of the patient's own characteristics?

Not Discussing Sex Directly

Use of language, indirect/vague/open-ended language. This code relates to how both patients and professionals talk about sex. This includes patients making a comment that suggests that sex is a concern, a "loaded comment" or possibly a jokey or other suggestion.

Professionals may also talk about sex in a vague, indirect manner (both to each other and to patients).

Sex is rarely discussed explicitly – is this because people are uncomfortable/perceive that others will be made uncomfortable?

Asking a General Question to Invite Patients to Discuss Sex

A question that suggests the topic, gives permission, gently opens out the possibility of speaking about sexuality.

This has been in the form of a “is there anything you would like to ask?” or “have you noticed any other changes”

Quite ambiguous

An opening the door technique

May not be meant by the professional as a way of getting to sexual topics, but might be used by the patient as such

Coming to the Topic of Sexuality Through Another Topic or Task

“Get my foot in the door” “breaking the ice” the route in

This may be a deliberate route in by the professional to get to the topic of sexuality, or (more often) the topic may come up through a related topic/task, areas that touch on sexuality but not in an explicit/obvious way. Other topics which overlap with/impact on sex.

Professional may become aware of sexual issues in a subtle way through these topics, or these topics may give patients the opportunity to

This might include:

Relationships (assessment of carer relationship, relationship changes, referral related to relationship problems)

Continence/catheters

Bed arrangements

Movement/exercise (and fatigue)

In the context of asking questions about other personal/intimate areas

Providing Leaflet About Sexual Changes

Professionals often provide SA leaflets, seen as a good source of information. Some professionals were aware that SA do have a leaflet about sexual changes, and spoke about providing this or how it could be provided. It was not standard practice for all staff to provide it, it has not been easily available for patients. It might be used as a professional's method of addressing a concern (provide information) or as a way of facilitating discussion. Professionals who were not aware of the SA leaflet did speak about the need to have one, written material to give out.

Why is a written leaflet seen as the best method? Is this what patients would prefer? Are they helpful? (Aware of research looking at these leaflets, may not be as helpful as professionals think) Is this an "easy option"? It might help a professional get out of speaking about sex with the patient. Written information may be more comfortable for both patients and professionals.

Medical Review as the First Step in Addressing a Sexual Concern

"to start with they'd have to talk to their doctor"

"first step was just about getting a medication review to ensure that you know because I was aware that you know some of the medications that people can be prescribed including an antidepressant for example can actually you know effect the sort of libido and ability to get an erection so I wanted to check that out"

The doctor is seen as the appropriate person to sign-post to/refer on to, to review a patient once a sexual concern has been brought up. This may reflect the view that sexual issues are a medical concern, seems to particularly relate to erectile dysfunction which seems to have been the type of issue that came up the most, also issues relating to blood pressure.

Could be the stroke consultant or the GP. Does this make a difference depending on whether the doctor is in the team/close link or in a different service? Is this needed, or is this staff avoiding addressing the concern themselves?

Sign-Posting Them in the Right Direction

This would frequently be the response of a professional to a patient bringing up a sexual issue. Unclear if this is appropriate referring on or avoiding/"passing the buck". Does require professional to be aware of supporting services, though they may just refer back to GP. Why do they not feel they can deal with the issue themselves/within the team? Is it seen as requiring "specialist" knowledge/skills

Professional feeling uncomfortable talking about sex

Professionals express their own discomfort talking about sex or are aware of other professionals' discomfort. Often difficult to know what to attribute this too. Sometimes discomfort evident in interview one-to-one.

Topic of Sex Not Coming Up Often/Hadn't Expected Sexual Issues to Come Up

Low frequency with which topic of sex/sexual issues come up. Few staff have experience of it coming up often.

Not a very useful code but reflects environment/context

Few participants had anticipated that sexual issues might be part of their work in stroke rehabilitation.

Training rarely covered sexual issues so did not lead them to expect that they would come up. Also most participants had had very few experiences of sexual issues coming up, so their expectation may have matched the reality (although is this because there is no opportunity

for this issues to come up?)

Perception That Many People in General are not Comfortable Talking About Sex /Patient Talking Openly About Sex/Unusual for a Patient to Talk Openly About Sex

View that people on the whole are usually not comfortable talking about sex – stated as a fact, well-known, people are often not open.

Rarely qualified with examples, this seems to be generally accepted but has not been “tested out” as professionals do not have to talk about sex, so they don’t get to see if this is true. Self-confirming – don’t ask, people don’t bring up – therefore they are not comfortable/it is not a concern?

Patients who talk openly about sex are seen as unusual. These instances often forced the professional to act, or to think about their practice. This can reveal gaps in the professional’s knowledge, things they feel uncomfortable with or where there is no given procedure to address concerns

Not Knowing What to do if Someone Does Bring up a Sexual Issue/ Not Feeling That I Could Address a Sexual Issue/ Feeling or Thinking That I Didn't Know About Sexual Issues

Participant not knowing what to do if a patient brings up a sexual issue. A sense that is nothing they could provide, that it would need to be provided by a specialist professional who has specialist knowledge. Inability to transfer knowledge from other areas.

Sometimes this is based on experiences of being asked a question that they could not answer, though more often considering that if it did come up they would not know what to do. Lack of a clear pathway, what to actually do “What’s the point in asking if you’re not doing to do anything?”

A sense of one's own lack of knowledge in relation to sexual issues/areas. Interesting that participants see this as being a specialist area of "knowledge" and somehow do not access more "general knowledge" that they may have about sex or transferable knowledge from other areas (e.g. movement in physio). Few professionals had received any particular training on these areas, or had much experience of them coming up at work (an assumption that it is something you can be taught?)

Sex Not Included on Assessment Forms

"Well I think it's just a simple thing is it's not on the forms so we don't have to it's not on our assessment criteria so we don't ..."

Assessment forms used for initial assessment, used by all staff members at early stage. Very important position within the rehabilitation. The time for screening, impacts on plans for intervention and referrals. Pressure on timing, what is included.

Why are professionals so reliant on these assessment forms? When might a professional deviate from the standard assessment? Would this be difficult to do? Does the assessment form legitimise certain questions (although some participants had experience of using forms with a sex question, and even then it wasn't always asked). How do professionals make decisions about which questions to ask, how "standard" is this standard form?

Does this excuse personal discomfort? Why is sex not included on the form? What would it take for it to be included?

Necessary for the Patient to Bring the Topic of Sex Up

"if people want to talk about it they do"

“you deal with it when they bring it up “

The patient has to “make the first move” and bring up sexuality in order for it to be discussed and addressed. The professional would wait for them to do so, and would not act to invite the discussion or ask directly.

This seems to be related to the lack of a direct question/point about sex on a standard assessment form. So professional is not prompted to ask and is not given any “easy” means of bringing the topic up.

Concerns that asking about sex might be viewed as inappropriate/rude/intrusive, so this may reflect a desire to respect the patient’s privacy and allow them to decide the terms on which they discuss sex. Person-centred?

Places responsibility on patient to bring up their own sexual needs (if they want to talk about it they do) without consideration that this might be difficult and require facilitation.

(Own thoughts - Do patients wonder if it will be acceptable to talk about sex? Worry about how this might affect the professional? Parallel process) Patient setting the agenda.

Is this an way of excusing personal discomfort about talking about sex? Put responsibility on patient not professional. Does not fit with held view that all professionals have relevant responsibility to identify issues.

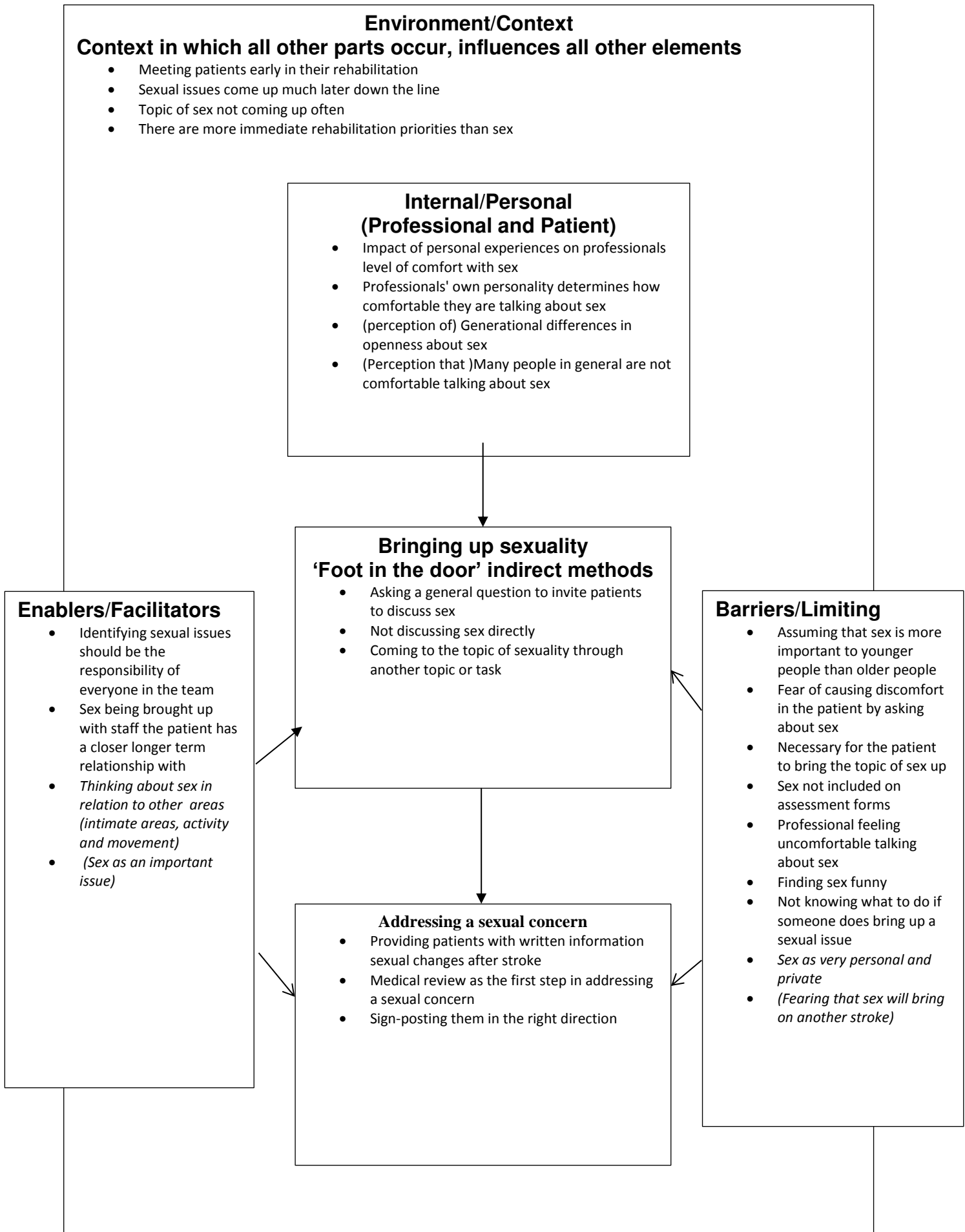
Finding Sex Funny

“it’s talked about in a really jokey way”

“the physical side of things ...and the (small laugh) logistics” Many of the participants laughed during their interview in relation to talking about sex – why is sex funny? Does this relate to comfort? People may laugh when they are uncomfortable/awkward Is sex

inherently funny? Is this how it is popularly presented (films, comedy, rude jokes). Also related – sex as entertainment, staff gossiping about cases with a sexual element

Appendix O – Early Diagramming



Appendix P: Coding evolution

Raw Data:

"I think that the fear I guess is that if you were to bring up something as personal as somebody's sex life as part of a physiotherapy session that might damage your therapeutic relationship with the patient and you might lose out on more than just the discussion about their sexuality" (Participant 1)



Open-coding:

"Fearing that bringing up sex will damage therapeutic relationship" (Using participants' own words)

"Bringing up sex could jeopardise rehabilitation"

Memo written: Is it likely that bringing up sex could damage a therapeutic relationship or rehabilitation activity? Has this ever happened for participants? If this comes up in other interviews, consider asking for an example.



Selective coding:

Open code merged with other open codes that related to healthcare professionals worrying about the negative impact bringing up sex could have on a patient. Other merged open codes included *"It feels intrusive"* and *"They'd say it's none of your business"*, to create *"Fear of causing patient discomfort"*



Theoretical coding:

Memo written about the selective code (see Appendix 14 for further detail): This code appears to relate more to the professional's own discomfort (at potentially causing another distress), and what they predict will be the patient's reaction. Rarely qualified with examples from practice. This code is acting to make professionals hold back from approaching the subject with patients, it appears to be strongly held and is getting in the way of action. This code seems to be about perceptions of patients (rather than actual experiences of patients). In this way it is similar to my other concepts *"People are uncomfortable talking about sex"* (reflecting the idea that it is the norm to be uncomfortable talking about sex) and *"Older people are less open about sex"* (perception of generational differences in openness). All of these views seem to be stated as "fact" and used as a way of explaining why a professional did not approach the topic of sexuality with a patient.

"Fear of causing patient discomfort", *"People are uncomfortable talking about sex"* and *"Older people are less open about sex"* appear to all be aspects of the category *"Perceiving patients as uncomfortable talking about sex"*. This category seems to interact with *"level of comfort"* and limit *"engaging in action"*.

Appendix Q – Grounded Theory Main Categories and Sub-Categories

Higher-Level Code: Personal Level of Comfort

| Category | Sub-categories | No. of participants | Example(s) of each category |
|--|---|---------------------|---|
| Personal level of comfort with sexuality (continuum) | Personality | 5 | Participant 4 - "I think it actually comes down to personality some people are not comfortable talking about sex" Participant 10 - "I mean I'll talk to anybody! ...And that's I that's my personality that's it I'm guessing what more than anything else" |
| | How you talk about sex in your personal life | 4 | Participant 2 - "It's perhaps your own.. Experience as well in that... do I talk about sexuality and erm sex-lives with my friends no I don't" |
| | I've seen a lot in my life | 6 | Participant 9 - "P – I think so (other staff) probably never had to discuss that with anyone and never been... what.... Perhaps not done sort of the things I've done in my life that you think "Well I've seen all that anyway" so just talking about sex... you know it's not gonna gonna bother me" |
| | Having more experiences of working with sexual issues | 10 | Participant 1 - "The fact that it has never really come up before then, when I've been working with people, whatever age they were um... it shouldn't really have been so unexpected I guess" Participant 10 - "You don't do (number) years of nursing um and start to be phased by things you know" |

Higher-Level Code: Barriers

| Category | Sub-categories | No. of participants | Example(s) of each category |
|--|--|---------------------|--|
| The environment of stroke rehabilitation is not supportive | Professionals are more involved before the time when sexual issues come up | 7 | <p>Participant 6 - "When people have settled in at home um when the dust has settled a little bit and then the person who's had the stroke tends to realise there are certain things that they're struggling more with"</p> <p>Participant 11 - "Once our the patients get home and then they talk about having sexual relations that's when it sort of kicks in that everything the realisation that actually "Can we do it? Are we allowed to do it?" you know all those things that they didn't probably enter their head..."</p> <p>Participant 4 - "If it comes up by the time it comes up for most people they've actually been discharged from most of the teams"</p> |
| | It's not on the form so we don't ask | 6 | Participant 2 - "It's just a simple thing is it's not on the forms so we don't have to it's not on our assessment criteria so we don't (ask)" |
| | More immediate rehabilitation priorities than sex | 6 | <p>Participant 1 - "This was somebody who had difficulty with.. more basic needs like washing dressing ..and that sort of thing and that felt like a more immediate rehabilitation goal than... than having sex"</p> <p>Participant 4 - "If you've got a stroke and you can't walk, eat or drink yourself your sex life is something that... is something that's distant rather than something that's an immediate thing that it might come up some time after your stroke"</p> |
| | Inappropriate locations for discussing sex | 6 | Participant 7 - "That's very sort of different from our involvement which is in their house and they might have their children running around and might have you know...loads of people around" |
| | Being under time-pressure | 5 | Participant 8 - "We are under pressure to see more people and get a lot of... through-put" |

| | | | |
|--|--|----|---|
| I don't know enough | What do I do? | 10 | Participant 2 - "Maybe that's why we don't I don't ask much because I don't know what to ... what to do about these things really in a way so we're all we want to find solutions" Participant 6 - "Some of the therapists were saying 'Well you know I I wouldn't know what to do'" |
| | How do I talk about it? | 4 | Participant 2 - "it's words that I have trouble, you know, how do you bring it up what sort of words do you use how do you" Participant 8 - "Maybe some sort of leading question but it's again would have when and how that would be asked would be tricky" |
| | Who should it be? | 6 | Participant 5 - "I honestly don't know who it should be that addresses it" |
| | It's complicated | 5 | Participant 6 - "It feels so much more complicated in stroke rehab" |
| Perceiving patients as uncomfortable talking about sex | Fear of causing patient discomfort | 9 | Participant 3 - "That's feeling kind of intrusive you know asking those...those kinds of questions" Participant 6 - "I feel like 'Am I going to offend you by... talking about this?'" |
| | People are uncomfortable talking about sex | 8 | Participant 1 - "They were fairly unusual couple in that they were very open about sex generally" Participant 4 - "Culturally that's not something that people are very comfortable actually talking about" |
| | Older people are less open about sex | 5 | Participant 4 - "An age where they didn't talk about sex" |
| It is the patient's responsibility | Always waiting for them to bring it up | 7 | Participant 5 - "I wouldn't bring it up unless they did" |

| | | | |
|--------------------------|----------------------|---|--|
| Finding sex entertaining | Laughing about sex | 5 | Participant 6 - "it's talked about in a really jokey way" Participant 7 - "Yeah without going into the nitty gritty it's hard to explain (laughs)" |
| | Sex as gossip-worthy | 3 | Participant 3 - "It was quite well-known and I felt that that must have been quite difficult for her actually you know knowing that everybody knew that it you know had happened while she was having sex" |

Higher-level code: Enablers

| Category | Sub-categories | No. of participants | Example(s) of each category |
|---|---|---------------------|---|
| Realising that sex is an important part of someone's life | It was obviously important to them | 7 | Participant 5 - "It was obviously quite an important part of his life" |
| | Sex as part of someone's life | 4 | Participant 6 - "Reminding myself that this is an important part of people's lives" |
| Realising that sexual issues could be part of the work of all professionals in the team | It should be everyone | 6 | Participant 6 - "When in fact it's you know kind of everyone's responsibility really to just inquire" Participant 10 - "I don't think it matters <i>who</i> it is so long as you know they are open and honest and um and feel comfortable doing it" |
| | Sexuality should be part of holistic care | 4 | Participant 2 - "It (sexuality) should be a part of a holistic assessment" |
| | It could be me | 8 | Participant 3 - "Interviewer - Do you feel like addressing issues relating to sexuality ought to come under your professional remit? Participant – Yeah no definitely" |
| | It could be someone else | 9 | Participant 7 - "We've got psychologists attached to the team so hopefully that's something they would address" |
| Drawing on experience of other conditions | Sexuality in relation to MS | 3 | Participant 5 - "I would say it (sexuality) comes up more often in other long-term neurological conditions like MS" |
| | Sexuality relating to TBI | 2 | Participant 4 - "With acquired brain injury it comes up a lot" |
| | Sexuality related to Parkinson's | 1 | Participant 1 - "He'd been asked to come and talk to us about it from a patient's standpoint and he brought up issues relating to sexuality in that he'd had to have treatment for erectile dysfunction and as a result of his Parkinson's disease" |

| | | | |
|---|---|---|--|
| Having a good quality relationship with patient | Having a longer-term relationship with a patient | 7 | Participant 7 - "The other people who get to know the patients better sometimes than the qualified therapists are the rehab assistants because although they wouldn't necessarily be best placed to answer the queries it might well come up because they're seeing them perhaps week after week perhaps twice a week and if someone's struggling they're the people they end up confiding in sometimes" |
| | Developing a closer relationship with a patient | 6 | Participant 4 - "I wouldn't really expect anyone I don't know very well to ask (about sex)" |
| | Perceived similarity between professional and patient | 3 | Participant 4 - "I don't think somebody's going to ask somebody in their twenties about it" Participant 6 - "He was very suspicious of me coming in because I'm a psychologist but also because I'm a young woman" |
| | The patient feels that they can talk to you | 5 | Participant 4 - "Patients feeling that they can ask and you having the right kind of um (pause) you're projecting um a kind of um attitude that people can ask and you're not going to be offended or embarrassed or whatever and then they feel that they can ask" |

Higher-level code: Engaging in Action

| Category | Sub-categories | No. of participants | Example(s) of each category |
|--------------------|-------------------------------|---------------------|--|
| "Foot in the door" | Talking about sex indirectly | 9 | <p>Participant 2 - "Even... when it was discussed... it probably wasn't... discussed... well in terms of sexuality and what's your sex life like now that sort of thing it might have been er you know is there anything else that's changed you know used sort of discussed in that sort of way really"</p> <p>Participant 5 - "At the end of our assessments we tend to say 'Is there anything you'd like to ask us?' and that was his time to ask"</p> |
| | Breaking the ice | 7 | <p>Participant 1 - "From a more physiological point of view I to think about it like that makes it slightly easier um and then and that almost opens up an avenue for conversation with a patient in that you know you can talk about that bit of it and if that have any further questions perhaps that almost breaks the ice a little bit for them to ask things the more in depth things that they might want to ask"</p> <p>Participant 2 - "It would always be a practical you know get my foot in the door through a practical reason"</p> |
| | Picking up on a patient's cue | 6 | <p>Participant 5 - "He brought it up in um... in a in a very jovial manner but um actually with deep meaning behind it"</p> <p>Participant 6 - "You come away from a session you think "Mm I think something else is going on here that's not being spoken about"</p> |

| | | | |
|--|--|---|--|
| Patient bringing up sex directly | Patient asks a question | 6 | Participant 3 - "She actually wanted to ask she said you know was it ok to resume to have sex" Participant 4 - "Asking if they could have sex because asking about how it effects your blood pressure and whether they felt that this was something that would be bad with the stroke" |
| | Patient brings up a concern | 5 | Participant 1 - "They both talked about it quite openly in our assessment session" Participant 3 - "He was able to say it so clearly um you know and it he didn't seem embarrassed by it he was just stating quite sort of matter of factly" |
| Offering an opportunity to discuss sex | Using a form for patients to indicate that they want information about sex | 2 | Participant 3 - "You know we could sort of add that on as you know please tick if you'd like some more information...That could be one way of sort of putting it back on the agenda for people" |
| | Asking the patient directly about sexuality | 5 | Participant 6 - "Sometimes you have to ask directly...You have to be curious about that person's relationship" |
| | Indicating sex is amongst the many areas we cover | 1 | Participant 7 - "One of the slides on the presentation it lists how your fatigue might affect you and it gives a list of all the areas of your life and I have a feeling that probably sex comes on the list so it is actually written on the screen at some point so that might then give people permission probably to... bring it up" |
| | Legitimising the topic early on | 1 | Participant 3 - "It's just creating that it's ok to talk about this and even if you don't want to talk about it at the moment you can come back and ask us...You know if there are issues in the future" |

| | | | |
|--------------------------|-----------------------------------|---|--|
| Actually doing something | Pass it on to somebody else | 8 | Participant 4 - "People would tend to think that they would then pass it on to somebody else" Participant 7 - "We're probably more likely to refer on" |
| | Medical review is the first step | 8 | Participant 2 - "You just tend to say 'Contact your GP'" Participant 3 - "I felt that the first step was just about getting a medication review to ensure that you know because I was aware that you know some of the medications... can actually you know effect the sort of libido and ability to get an erection so I wanted to check that out " Participant 6 - "It's seen as a medical issue" |
| | Providing access to information | 7 | Participant 10 - "I have given out leaflets do the- there was a Stroke Association leaflet about sexual intercourse post-stroke" |
| | Just talking about things | 7 | Participant 9 - "Well I I'd listen to them if I could advice them I could if I couldn't I'd talk thought it with them" Participant 10 - "I tend to talk them through it erm... I... I've never given them step-by-steps instructions but they've never required that they've just wanted to say 'Is it ok... to do it?' Is it ok um you know the consequences the risks and all those things erm that's how it's normally been a conversation... Um I have" |
| | Discipline-specific interventions | 4 | Participant 4 - " If people are spasming when they're getting in positions for sex then you would actually talk to the physio about it about different things that they could try to stop" |

Appendix R – Quality Assurance Guidelines

Mays and Pope (2000) ask the following questions about the quality of a qualitative study:

- Worth or relevance—Was this piece of work worth doing at all? Has it contributed usefully to knowledge?
- Clarity of research question—If not at the outset of the study, by the end of the research process was the research question clear? Was the researcher able to set aside his or her research preconceptions?
- Appropriateness of the design to the question—Would a different method have been more appropriate? For example, if a causal hypothesis was being tested, was a qualitative approach really appropriate?
- Context—Is the context or setting adequately described so that the reader could relate the findings to other settings?
- Sampling—Did the sample include the full range of possible cases or settings so that conceptual rather than statistical generalisations could be made (that is, more than convenience sampling)? If appropriate, were efforts made to obtain data that might contradict or modify the analysis by extending the sample (for example, to a different type of area)?
- Data collection and analysis—Were the data collection and analysis procedures systematic? Was an “audit trail” provided such that someone else could repeat each stage, including the analysis? How well did the analysis succeed in incorporating all the observations? To what extent did the analysis develop concepts and categories capable of explaining key processes or respondents' accounts or observations? Was it possible to follow the iteration between data and the explanations for the data (theory)? Did the researcher search for disconfirming cases?
- Reflexivity of the account—Did the researcher self consciously assess the likely impact of the methods used on the data obtained? Were sufficient data included in the reports of the study to provide sufficient evidence for readers to assess whether analytical criteria had been met?

Appendix S – Summary of Findings for Participants

Thank you very much for taking part in my research project “**A grounded theory of how healthcare professionals engage with sexual concerns within stroke rehabilitation**”. With your help we have generated some interesting and useful findings about this often neglected area. I am writing to provide a summary of the key findings.

What was this study about?

The study aimed to explore how staff working in stroke rehabilitation work with sexual issues. Sexual difficulties after stroke are common, and this study hoped to find ways of helping staff to support their patients.

Who was involved?

10 healthcare professionals took part, from a variety of disciplines. Participants came from both inpatient and community rehabilitation services, so covered many different aspects of stroke rehabilitation.

What was involved?

I interviewed staff about their experiences of sexual issues coming up within their work. I asked them about what had helped in these situations and what had been difficult. We discussed how these issues would be best managed and how different professionals within the team could be involved. I recorded the interviews and analysed the information within them using grounded theory methodology.

What did I find?

Several different themes came out of the interviews and I created a model about how these different aspects interact. Some of the main factors were as follows:

How do professionals actually engage with sexual issues in stroke rehabilitation?

When the patient did bring up a sexual concern, usually this related to worrying about whether it was safe to have sex after their stroke, or concerns about erectile functioning. Other staff had had experiences of patients having difficulty with movements involved in sex, relationship problems, feeling unattractive or feeling unable to carry out their usual roles as a husband/wife or man/woman.

Professionals told me that they rarely asked patients direct questions about sex, and that often this did not feel appropriate. Instead they tended to find indirect ways of approaching the topic. This included coming to talking about sex through another topic, such as incontinence or sleeping arrangements, or using very general and tentative language to approach the topic. Sometimes professionals picked up on a subtle cue from patients that they wanted to discuss sexuality. At other times professionals found ways of letting patients know that if they wanted to talk about sex, they could and this was acceptable.

Many professionals said they wouldn't know what to do if a patient brought a sexual problem to them. However, those with more experience had found that often the patient just needed a space to talk about their worries, be listened to and to receive some reassurance. Occasionally a referral to another professional or service was necessary for a particular intervention (e.g. talking therapy or physiotherapy around movement).

Sometimes patients just wanted a bit more information, and staff provided them with the

Stroke Association's leaflet on Sex after Stroke and sometimes discussed the content with them.

What helps professionals to work with sexual issues, and what gets in the way?

Personal level of comfort

Professionals varied in how comfortable they felt with the topic of sexuality. They related this to their own personality, life experiences and also work experiences. Their level of comfort plays a large role in whether they felt able to talk to patients about sexual issues and support them with their concerns.

Worrying about not knowing enough

Professionals often thought that they did not know enough about sexuality. They did not know how to talk about it with patients or what should be done to help. Sexuality was seen as a "difficult" area that needed input from a specialist.

Organisational barriers

Sexual problems tended to come up for patients later on in rehabilitation, often when professionals were less involved. Sexuality was not included in local stroke policies or standard assessments, and this made it difficult to know when and how to bring it up. The environments professionals worked in often lacked privacy and the time they could spend with patients was limited.

Worrying about upsetting patients

Professionals did not want to cause their patients discomfort and worried that this could jeopardise the therapy. However, most professionals could not think of occasions when bringing up sex had had a very bad impact on rehabilitation.

Having a good therapeutic relationship

Professionals agreed that it was important to have a strong relationship with a patient before they might feel able to talk to you about sex. Having more contact over a longer period of time helped this relationship to grow. Some professionals gave off an attitude that they were open-minded and comfortable so patients felt about to approach them.

Who should it be?

There was uncertainty about which professional should have responsibility for sexual issues. However, most professionals saw that there was something they themselves could contribute. All professionals could be involved in assessing and talking about sexuality with patients, though some interventions would require a particular professional.

Negative attitudes towards patients and sexuality

Professionals aimed to be open-minded and inclusive, but sometimes they expressed subtle views about patients and sex that seemed to get in the way of supporting patients. Sex was viewed as of low importance to older people and those with disabilities. Older people were viewed as being uncomfortable talking about sex, and professionals were often surprised

when they did talk about it. Professionals believed it was the responsibility of the patient to bring up the issue and sometimes sex was treated as funny or a topic for gossip.

Summary

This study has revealed some new insights into how staff are working with the sexual issues that come up within stroke rehabilitation. Guidelines suggest that all patients get asked directly about their sexual concerns. However, the results of this study suggested that this might not be appropriate. Not all staff and patients will feel comfortable using such a direct approach, and developing less direct ways of approaching the topic may be more suitable and comfortable.

The results suggest that more could be done to make sexuality a legitimate topic within rehabilitation and to let both patients and staff know that it is ok to talk about it. Many staff worry that they do not know enough about sexuality to support patients, but the clinical skills they already have are relevant and useful. Training could help support staff to apply these skills to working with sexual issues.

Alexandra Richards**Trainee Clinical Psychologist**

Appendix T – Summary of Findings for Trusts R&D Departments

A grounded theory of how healthcare professionals engage with sexual concerns within stroke rehabilitation

Background

Sexual difficulties are common after stroke (Bugnicourt, Hamy, Canaple, Lamy & Legreand, 2014; Rosenbaum, Vadas, & Kalichman, 2014) and current clinical guidelines recommend that patients are asked about their sexual concerns within rehabilitation (Royal College of Physicians, 2012). However, evidence suggests that the topic is often neglected and patients and their partners are left unsupported (McLaughlin & Cregan, 2005; Schmitz & Finkelstein, 2010).

Research aims

This study intended to explore how healthcare professionals approach and engage with sexual issues within rehabilitation. The aim was to investigate what makes this process difficult and what would support professionals to better meet the needs of patients.

Method

The sample consisted of 10 healthcare professionals who worked within stroke rehabilitation. This included a variety of disciplines and spanned the inpatient and community stages of rehabilitation. Grounded theory analysis and semi-structured open-ended interviews were used to gain detailed data about participants' experiences and attitudes about the area (Urquhart, 2013).

Findings

Fourteen major categories and a theoretical model were suggested by the data. These categories grouped together into four sections: "**Personal level of comfort**" (the impact of personality and experience on how professionals felt about sexuality), "**Barriers**" that limited professionals ability to engage with sexual issues, "**Enablers**" that facilitated them and "**Engaging in action**" describing the different ways that professionals acted in relation to sexual issues.

Professionals' own level of comfort interacted with a series of barriers. These included "**I don't know enough**" (perception of lack of knowledge and skill), "**Perceiving patients as uncomfortable talking about sex**" (fearing causing the patient discomfort), "**The environment of stroke rehabilitation is not supportive**" (how the organisation and context does not legitimise sexuality as an area for work), "**It is the patient's responsibility**" (waiting for the patient to bring up sexuality themselves) and "**Finding sex entertaining**". Factors that helped professionals to engage with patients around sexual issues were: "**Realising that sex is an important part of someone's life**", "**Realising that sexual issues could be part of the work of all professionals in the team**", "**Drawing on experience of other conditions**" and "**Having a good quality relationship with the patient**" (longer-term involvement and a good rapport).

When professionals did engage with sexual issues, this was done in a number of ways including "**Foot in the door**" (indirect methods of approaching the topic of sexuality),

“Offering an opportunity to discuss sex” (giving the patient permission) and **“Patient brings up sex directly”** (responding to a question or raised concern). This could be followed by **“Actually doing something”** (providing support or intervention). Often the required intervention was the provision of reassurance and sometimes information.

Clinical Implications

The study highlighted that measures could be taken to legitimise the topic of sexuality within stroke rehabilitation and that professionals require some support to enable them to work with sexual issues.

Training could support professionals to use transferable skills in supporting patients experiencing post-stroke sexual difficulties. A focus on developing communication skills could also help professionals to feel more confident about initiating conversations about sexuality. Additionally, reflecting on and challenging negative attitudes towards older people and those with disabilities could improve practice. The PLISSIT model (Annon, 1976), which emphasises permission-giving and low-level interventions has been applied in sexuality training in other settings and appears to hold relevance for stroke rehabilitation. Participants’ practice was informed by local policy and procedures (such as standard assessment forms), and these did not include mention of sexuality. The development of a care pathway would support professionals in knowing how to address sexual issues. Sexual issues tend to come up later on in rehabilitation and require a longer-term relationship with a professional in order for the patient to feel comfortable bringing it up. This is somewhat at odds with usual practice, where professional energy is concentrated earlier on in the pathway and reduces over time. Addressing sexual concerns may require longer-term involvement and follow-up, to ensure that that sexuality does not get “lost” after more “immediate” concerns are addressed.

Alexandra Richards

Trainee Clinical Psychologist

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Appendix U – Journal Submission Guidelines

Disability and Rehabilitation

Instructions for Authors

Disability and Rehabilitation is an international interdisciplinary journal and particularly welcomes contributions from a wide range of professional groups, including medical practitioners, occupational therapists, physiotherapists, speech and language therapists, clinical psychologists and those involved in nursing, education and engineering.

Disability and Rehabilitation is organised into sections: Reviews; Research Papers; Case Studies; Perspectives on Rehabilitation; reports on Rehabilitation in Practice, Education and Training and Correspondence.

Special Issues and specific sections on contemporary themes of interest to the Journal's readership are published. Please contact the Editor for more information.



Submissions and Peer-Review

All submissions should be made online at **Disability and Rehabilitation**'s ScholarOne Manuscripts site: <http://mc.manuscriptcentral.com/dandr>.

Authors are given the option to remain anonymous during the peer-review process. Authors will be able to indicate whether their paper is „Anonymous“ or „Not Anonymous“ during manuscript submission, and should pay particular attention to the below:

Authors who wish to remain anonymous should prepare a complete text with information identifying the author(s) removed. This should be uploaded as the “Main Document” and will be sent to the referees. Any acknowledgements and the Declaration of Interest statement must be included but should be worded mindful that these sections will be made available to referees.

Authors who wish to be identified should include the name(s) and affiliation(s) of author(s) on the first page of the manuscript. The complete text should be uploaded as the “Main Document”.

All submissions should include a separate title page that contains contact information for the author(s). This should be uploaded as a “Title Page” and will not be sent to referees.

If a paper is deemed to be acceptable for publication pending minor revision, the author(s) names may be disclosed to the referees when the Editor's decision is made, irrespective of whether the author's name(s) were included as part of the original submission. Every effort will be made to keep the author(s) name(s) anonymous, if required, should the paper require extensive revision and further peer-review. If authors wish to remain anonymous throughout the second round of peer-review, they

are reminded not to include identifying information in the „Authors“ Response“ section during the upload of their revised paper.

Every paper that is revised and resubmitted must clearly indicate the parts of the manuscript that contain amendments, by highlighting the revised text in a different colour or by using „Track Changes“ (for minor revisions).

Please contact the Editor if you require more information.

Systematic Reviews should be submitted as a „Review“ and Narrative Reviews should be submitted as „Perspectives in Rehabilitation“. All Systematic Reviews will be automatically submitted for the annual Best Review Paper competition.

Education and Training

This is a new section for the journal. It will publish papers relating to the education and professional training of those working in the field of rehabilitation. Papers are encouraged which develop innovatory approaches to this process and provide multi-disciplinary and international comparisons for those working in the field. Through this new section it is intended to contribute towards the development of education and training within these professional groupings.

Papers should be submitted with any tables, figures, or photographs, all of which should be of high quality suitable for reproduction. Submissions should be in English presented in double line spacing. Submissions should include, where appropriate, a formal statement that ethical consent for the work to be carried out has been given. Photographs of patients should be avoided, but if essential, patients' consent in writing must accompany manuscript. It is not sufficient to mask identity by covering the patients' eyes.

Word Limit

There is no stated word limit to papers submitted to Disability and Rehabilitation. It should however be noted that space is at a premium and therefore succinct and well-constructed papers are more likely to be reviewed positively. However, the key to evaluating a paper will be the quality of the work along with the methodology adopted particularly for qualitative studies which do tend to be longer.

Disability and Rehabilitation considers all manuscripts at the Editor's discretion; the Editor's decision is final. Please see below for information on the Journal's Appeal Procedure.

Disability and Rehabilitation considers all manuscripts on the strict condition that they are the property (copyright) of the submitting author(s), have been submitted only to **Disability and Rehabilitation**, that they have not been published already, nor are they under consideration for publication, nor in press elsewhere. Authors who fail to adhere to this condition will be charged all costs which **Disability and Rehabilitation** incurs, and their papers will not be published. Copyright will be transferred to **Disability and Rehabilitation** and Informa UK Ltd., if the paper is accepted.

IMPLICATIONS FOR REHABILITATION

A feature of the Journal is a boxed insert on „Implications for Rehabilitation“. This box should include between two to four main bullet points drawing out the implications for rehabilitation for your paper.

All papers including reviews, research, rehabilitation in practice, perspectives on

rehabilitation, case studies and a new section on education and training for rehabilitation professionals must include this feature. This should be uploaded as a separate document through Manuscript Central as a single side of A4 during submission.

Included below are examples. If you have any questions, please contact the Editor.

Example 1: Leprosy

- Leprosy is a disabling disease which not only impacts physically but restricts quality of life often through stigmatisation.
- Reconstructive surgery is a technique available to this group.
- In a relatively small sample this study shows participation and social functioning improved after surgery.

Example 2: Multiple Sclerosis

- Exercise is an effective means of improving health and well-being experienced by people with multiple sclerosis (MS).
- People with MS have complex reasons for choosing to exercise or not.
- Individual structured programmes are most likely to be successful in encouraging exercise in this cohort.

Example 3: Community Based Rehabilitation

- Community Based Rehabilitation (CBR) is a Western concept that may not readily fit other cultures.
- CBR needs to be „owned“ by those involved and subject to re-interpretation to be effective in other cultures.

Manuscript Preparation

In writing your paper, you are encouraged to review articles in the area you are addressing which have been previously published in the Journal and where you feel appropriate, to reference them.

This will enhance context, coherence, and continuity for our readers.

File preparation and types

Manuscripts are preferred in Microsoft Word format (.doc files). Documents must be double-spaced, with margins of one inch on all sides. Tables and figures should not appear in the main text, but should be uploaded as separate files and designated with the appropriate file type upon submission. These should be submitted as “Image” files during submission. References should be given in Council of Science Editors (CSE) Citation & Sequence format (see References section for examples).

Structure of Paper

Manuscripts should be compiled in the following order: title page; abstract; main text; acknowledgments; Declaration of Interest statement; appendices (as appropriate); references; tables with captions (uploaded as separate files); figures with captions (uploaded as separate files).

An introductory section should state the purpose of the paper and give a brief account of previous work. New techniques and modifications should be described concisely but in sufficient detail to permit their evaluation; standard methods should simply be referenced. Experimental results should be presented in the most appropriate form, with sufficient explanation to assist their interpretation; their discussion should form a distinct section. Extensive tabulations will not be accepted unless their inclusion is essential.

Title Page

A title page should be provided comprising the manuscript title plus the full names and affiliations of all authors involved in the preparation of the manuscript. One author should be clearly designated as the corresponding author and full contact information, including phone number and email address, provided for this person. Keywords that are not in the title should also be included on the title page. The keywords will assist indexers in cross indexing the article. The title page should be uploaded separately to the main manuscript and designated as “title page” on ScholarOne Manuscripts. This will not get sent to referees.

Abstracts

Structured abstracts are required for all papers, and should be submitted as detailed below, following the title page, preceding the main text.

Purpose State the main aims and objectives of the paper.

Method Describe the design, and methodological procedures adopted.

Results Present the main results.

Conclusions State the conclusions that have been drawn and their relevance to the study of disability and rehabilitation.

The abstract should not exceed 200 words.

Nomenclature and Units

All abbreviations and units should conform to SI practice. Drugs should be referred to by generic names; trade names of substances, their sources, and details of manufacturers of scientific instruments should be given only if the information is important to the evaluation of the experimental data.

Copyright Permission

Contributors are required to secure permission for the reproduction of any figure, table, or extensive (more than fifty word) extract from the text, from a source which is copyrighted - or owned - by a party other than Informa UK Ltd or the contributor.

This applies both to direct reproduction or 'derivative reproduction' - when the contributor has created a new figure or table which derives substantially from a copyrighted source.

Code of Experimental Ethics and Practice

Contributors are required to follow the procedures in force in their countries which govern the ethics of work done with human or animal subjects. The Code of Ethics of the World Medical Association (Declaration of Helsinki) represents a minimal requirement.

Tables, figures and illustrations

The same data should not be reproduced in both tables and figures. The usual statistical conventions should be used: a value written 10.0 ± 0.25 indicates the estimate for a statistic (e.g. a mean) followed by its standard error. A mean with an estimate of the standard deviation will be written $10.0 \text{ SD } 2.65$. Contributors reporting ages of subjects should specify carefully the age groupings: a group of children of ages e.g. 4.0 to 4.99 years may be designated 4 +; a group aged 3.50 to 4.49 years $4 \pm$ and a group all precisely 4.0 years, 4.0.

Tables and figures should be referred to in text as follows: figure 1, table 1, i.e. lower case. 'As seen in table [or figure] 1 ...' (not Tab., fig. or Fig).

The place at which a table or figure is to be inserted in the printed text should be indicated clearly on a manuscript:

Insert table 2 about here

Each table and/or figure must have a title that explains its purpose without reference to the text. The filename for the tables and/or figures should be descriptive of the graphic, e.g. table 1, figure 2a.

Tables

Tables should be used only when they can present information more efficiently than running text. Care should be taken to avoid any arrangement that unduly increases the depth of a table, and the column heads should be made as brief as possible, using abbreviations liberally. Lines of data should not be numbered nor run numbers given unless those numbers are needed for reference in the text. Columns should not contain only one or two entries, nor should the same entry be repeated numerous times consecutively. Tables should be grouped at the end of the manuscript on uploaded separately to the main body of the text.

Figures and illustrations

Figures must be uploaded separately and not embedded in the text. Avoid the use of colour and tints for purely aesthetic reasons. Figures should be produced as near to the finished size as possible. Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC). All files must be 300 dpi or higher. Please note that it is in the author's interest to provide the highest quality figure format possible. Please do not hesitate to contact our Production Department if you have any queries.

Acknowledgments and Declaration of Interest sections

Acknowledgments and Declaration of interest sections are different, and each has a specific purpose. The Acknowledgments section details special thanks, personal assistance, and dedications. Contributions from individuals who do not qualify for authorship should also be acknowledged here. Declarations of interest, however, refer to statements of financial support and/or statements of potential conflict of interest. Within this section also belongs disclosure of scientific writing assistance (use of an agency or agency/ freelance

Acknowledgments section

Any acknowledgments authors wish to make should be included in a separate headed section at the end of the manuscript preceding any appendices, and before the references section. Please do not incorporate acknowledgments into notes or biographical notes.

Declaration of Interest section

All declarations of interest must be outlined under the subheading “Declaration of interest”. If authors have no declarations of interest to report, this must be explicitly stated. The suggested, but not mandatory, wording in such an instance is: The authors report no declarations of interest. When submitting a paper via ScholarOne Manuscripts, the “Declaration of interest” field is compulsory (authors must either state the disclosures or report that there are none). If this section is left empty authors will not be able to progress with the submission.

Please note: for NIH/Wellcome-funded papers, the grant number(s) must be included in the Declaration of Interest statement.

[Click here to view our full Declaration of Interest Policy.](#)

Mathematics

[Click for more information on the presentation of mathematical text.](#)

References

References should follow the Council of Science Editors (CSE) Citation & Sequence format. Only works actually cited in the text should be included in the references. Indicate in the text with Arabic numbers inside square brackets. Spelling in the reference list should follow the original. References should then be listed in numerical order at the end of the article. Further examples and information can be found in *The CSE Manual for Authors, Editors, and Publishers, Seventh Edition*. Periodical abbreviations should follow the style given by *Index Medicus*.

Examples are provided as follows:

Journal article: [1] Steiner U, Klein J, Eiser E, Budkowski A, Fetters LJ. Complete wetting from polymer mixtures. *Science* 1992;258:1122-9.

Book chapter: [2] Kuret JA, Murad F. Adenohypophyseal hormones and related substances. In: Gilman AG, Rall TW, Nies AS, Taylor P, editors. *The pharmacological basis of therapeutics*. 8th ed. New York: Pergamon; 1990. p 1334-60.

Conference proceedings: [3] Irvin AD, Cunningham MP, Young AS, editors. *Advances in the control of Theileriosis*. International Conference held at the International Laboratory for Research on Animal Diseases; 1981 Feb 9-13; Nairobi. Boston: Martinus Nijhoff Publishers; 1981. 427 p.

Dissertations or Thesis: [4] Mangie ED. *A comparative study of the perceptions of illness in New Kingdom Egypt and Mesopotamia of the early first millennium* [dissertation]. Akron (OH): University of Akron; 1991. 160 p. Available from: University Microfilms, Ann Arbor MI; AAG9203425.

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APPEAL PROCEDURE

Disability and Rehabilitation and Disability and Rehabilitation: Assistive Technology

The Editors of both Journals will respond to appeals from Authors relating to papers which have been rejected.

The Author(s) should email the Editor outlining the concerns and making a case for why their paper should not have been rejected. The Editor will undertake one of two courses of action:

1: The Editor Accepts the Appeal

I. In this case the Editor will secure a further review making available confidentially the relevant information for the reviewer

II. The Editor on receiving the review will either accept the appeal and therefore invite a resubmission for further review; or reject the appeal and no further action will be taken.

III. If an appeal is rejected there will be no further right of appeal within the jurisdiction of the Journal.

2: The Editor does not uphold the Appeal

I. If the Editor does not accept the appeal and is not prepared to secure further review the decision will be referred to the Editor of the relevant affiliated Journal for independent consideration. In the case of *Disability and Rehabilitation*, the Editor of *Disability and Rehabilitation: Assistive Technology* will be contacted, and if an appeal is not upheld by the Editor of *Disability and Rehabilitation: Assistive Technology*, the Editor of *Disability and Rehabilitation* will be consulted.

II. The Editor will either confirm the decision or recommend that a further review be obtained.

III. Therefore, if both Editors agree that the appeal should not be upheld there will be no further right of appeal within the jurisdiction of the Journal.

Dave Muller, Editor in Chief, Disability and Rehabilitation

Marcia Scherer, Editor, Disability and Rehabilitation: Assistive Technology