

**Talking about sex after Traumatic Brain Injury: Perceptions and
experiences of professionals**

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Thesis abstract

Background: Research indicates that although 50-60% of people who have had a traumatic brain injury (TBI) experience changes in sexual functioning, sexuality issues remain largely unaddressed in rehabilitation. Studies have investigated professionals' perspectives about communicating about sexual issues with service-users² post-TBI, with a number of barriers being identified. However, as studies have tended to use quantitative methodologies, it was felt that qualitative research would provide a richer understanding.

Aim: This study aimed to explore professionals' perceptions and experiences of discussing sexuality with service-users who have had a TBI.

Method: This study employed a qualitative design. Purposeful sampling was used to recruit 24 participants from two local National Health Service (NHS) trusts, and from a national charity. Four focus groups were carried out with pre-existing teams of professionals, using a semi-structured interview schedule. Focus group data were transcribed verbatim and analysed using thematic analysis.

Results: Six main themes were derived from the analysis: 1) Sexuality after TBI is a specialist issue; 2) Sexuality is a sensitive subject; 3) Practicalities of discussing sexuality; 4) Roles and responsibilities; 5) Dilemmas about risk and vulnerabilities, and 6) Organisational and structural factors. Each of these themes have between two and five subthemes.

Conclusions and recommendations: In order that sexuality becomes accepted as an integral part of holistic rehabilitation, it is recommended that a more proactive approach is taken. It is recommended that sexuality is incorporated into assessments, and that written information is available for service-users. Support for professionals is also needed in the form of the development of policy, on-going training, and supervision.

² The term 'service-user' is used throughout this thesis instead of 'patient', because the former term is more generic and applicable to the services from which participants were drawn.

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Statement of contribution

Kerry Dyer was responsible for the design of this project, applying for ethical approval, reviewing the relevant literature, recruitment of participants, data collection, transcription, analysis and writing up the research.

Dr Roshan das Nair provided supervision and guidance throughout the research process. He was also responsible for independently coding the transcripts, reviewing themes, and reviewing the thematic map that was derived from the analysis.

Dr Nigel Schofield, Consultant Clinical Neuropsychologist also provided advice and guidance during the early stages of designing the project. A number of unnamed professionals were also responsible for disseminating the Participant information sheets within their organisations.

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Systematic Review

1.0 SYSTEMATIC REVIEW

Why don't healthcare professionals talk about sex? A systematic review of recent qualitative studies conducted in the United Kingdom.

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1.1 ABSTRACT

Introduction: Sexuality is considered to be an important aspect of holistic care, yet research has demonstrated that it is not routinely addressed in healthcare services. A greater understanding of why this is the case can be achieved through synthesizing individual qualitative studies investigating healthcare professionals' experiences of talking about sex. In doing so, policy makers and healthcare providers may be able to better address the sexual issues of service-users.

Aim: To gain an in-depth understanding of healthcare professionals' subjective experience of discussing sexuality with service-users, by identifying the factors that impede and facilitate such discussions.

Methods: Electronic databases and reference lists of published papers were searched in July 2011. Primary research studies were included in the review if they explored health professionals' experiences of discussing sexuality with adult service-users, used qualitative methods, and were conducted in the UK over the last ten years. Each study was reviewed and assessed. A secondary thematic analysis method was used where key themes were extracted and grouped, and key concepts explored.

Results: Nineteen interconnected themes emerged relating to healthcare professionals' experience of discussing sexuality with service-users, including fear about "opening up a can of worms", lack of time and resources, concern about knowledge and abilities, lack of training, worry about causing offence, personal discomfort, concern about own abilities, and a lack of awareness about sexual issues. Some themes were particularly marked relating to the sexuality of the opposite gender, black and ethnic minority groups, older service-users, non-heterosexual service-users, and those with intellectual disabilities.

Conclusions: The majority of healthcare professionals do not proactively discuss sexuality issues with service-users, and this warrants further attention. An understanding of the perceived barriers and facilitators indicates that interventions to improve the extent to which sexuality issues are addressed need to take organizational, structural, and personal factors into consideration.

1.2 INTRODUCTION

Sexuality has been defined as the way people experience themselves and each other as sexual beings [1] encompassing sexual activity, sexual orientation, eroticism, pleasure, intimacy, reproduction, as well as how we feel about our gender and our bodies [2]. Sexuality is now identified as a fundamental and natural need within everyone's life regardless of age or physical state [3] and is considered an important aspect of holistic (health) care [4].

Yet recent research from the UK has overwhelmingly demonstrated that issues of sexuality are not frequently addressed in the healthcare system. One survey found that although 60% of healthcare professionals (HCPs) agreed that sexual issues ought to be addressed as part of the holistic care of patients, only 6% initiated discussion on a frequent basis [5]. HCPs in this study identified a number of personal and organisational barriers to having such discussions, including lack of training (79%), lack of time (67%), and embarrassment (50%). These barriers have been identified in other UK studies, as well as fears of opening a "floodgate", concerns about not being able to cope with the issues raised, lack of policy, believing it is not their responsibility or outside their purview of care, religious views, and homophobia [6,7]. In addition, a number of service user characteristics have been found to affect the HCPs decision about whether to discuss sexual issues, including the patient's age (61%), physical wellbeing (54%), gender (52%), and whether they were in a stable relationship (42%) [5].

These quantitative studies have offered a useful starting point to understanding why sexual issues are infrequently addressed in the healthcare system. However, efforts to improve this aspect of healthcare will require a greater in-depth understanding of how these barriers operate, as well as how HCPs think these could be overcome. Qualitative research can be used to interpret the findings of quantitative studies by privileging HCPs' subjective accounts. However, the generalizability of these studies is limited by small sample sizes, to the unique population being studied, and to the researchers' subjective

interpretation of the data [8]. A broader use of the findings may be possible if individual qualitative studies in this area could be synthesized to identify similar themes across various studies; hence the current review. It is hoped that by identifying these barriers, as well as the factors which facilitate discussions about sexuality between HCPs and service-users, policy makers and healthcare providers will be able to better address the sexual issues of service-users.

However, there is considerable disagreement among qualitative researchers over the appropriateness of attempting to review and integrate individual qualitative studies [9–11], and where a researcher stands in this debate is likely to be dependent on their ontological, epistemological and methodological position [12]. Within a postmodernist epistemology, it is perhaps inappropriate to synthesize individual qualitative studies, as study findings are specific to a particular context at a particular point in time [12]. This review, however, operates on the assumptions that it is both possible, and desirable, to integrate qualitative research in order to build a picture of the empirical work which could better inform healthcare policy and practice. However, it is acknowledged that the meaning of the concept of “sexuality” (as well as sexual morals and tolerance levels) are highly dependent on time and culture, and that this meaning could be tragically lost if it is detached from its context by transferring it to a new setting. It is for this reason that this review has been limited to include only studies from the United Kingdom (UK) and to those published over the last ten years.

1.3 AIM

This review aims to synthesize the findings from multiple qualitative studies in order to gain an in-depth understanding of HCPs’ subjective experience of discussing sexuality with service-users, by identifying the factors that impede (barriers) and facilitate (facilitators) such discussions in clinical practice.

1.4 METHODS

1.4.1 Stage 1: Systematic literature search

Firstly, a series of a priori inclusion/exclusion criteria were defined. Studies were included in the review if they:

- a) Included HCPs as participants. HCPs were defined as persons who work with people with illness or disability (studies which included HCPs *and* service-users were also included, however only the analysis of the former was extracted for the purpose of this review);
- b) Explored HCPs' experience of discussing sexuality with adult service-users (i.e., over the age of 18);
- c) Involved primary research studies (i.e., not systematic reviews, opinion pieces, or editorials);
- d) Used a qualitative method of data collection and analysis (studies which used a mixed-method design were included, however only the qualitative data was extracted for the purpose of this review);
- e) Were published within the last ten years (2001-2011);
- f) Were carried out in the UK.

A systematic search was conducted on the Medline, EMBASE, PsycINFO and British Nursing Index (BNI) electronic bibliographic databases in July 2011. Together these databases represent the disciplines of medicine, nursing and social sciences. Alerts were then set up on these databases to highlight new relevant studies published between the initial searches until the time of analysis.

Across all databases, groups of terms were combined relating to three specific parameters: a) terms relating to sexuality, b) terms relating to the HCPs' experience of communicating with service-users, and c) terms relating to the qualitative research design. Where possible, subject headings were selected and exploded in order to retrieve articles where different authors may have used different terminology for the same concept. Where subject headings were not available, free-text search terms were used.

Reference lists of each article identified as being relevant were then searched to identify further potential research studies. Finally, Google Scholar was searched using the keywords *(staff OR HCP) AND (sexuality OR sexual)* (limiting to the years 2001-2011), and the first 100 results were checked.

All citations were initially checked for relevance by checking the title by the first author (KD). Where there was not enough information in the title to ascertain whether the research was appropriate for inclusion, the abstract was examined. Where there was not enough information in an abstract (or where an abstract was unavailable), full text versions were obtained. This list was appraised by the second author (RdN). The majority of citations were excluded at this stage because they were not specifically concerned with HCPs' perceptions of the barriers to discussing sexuality with clients, or because were not primary qualitative research.

Six articles were located from the database search [13–18] and two additional articles were identified from checking reference lists [19,20]. One other article was also identified through reference lists [21], however it was not included as it was clearly a duplication of another article included in the review (this was acknowledged by the authors). No additional articles were identified through searching Google Scholar.

Eight articles were therefore included in the final review [13–20]. It was apparent that some articles reported on findings from the same study, which was evident from the authors, location and sample size being the same (articles 14-17 reported on findings from the same study, and articles 18 and 20 reported on findings from the same study). Nevertheless, it was decided that all articles would be included in the review given that the data was analysed with different aims and objectives in mind.

1.4.2 Stage 2: General characteristics

The following information was abstracted from the articles: study aims, sample size and composition, study location, data collection method, data analysis method, and key findings. This coding frame was developed based on those used in previous qualitative systematic reviews (e.g. see [8,22–24]).

1.4.3 Stage 3: Critical appraisal

Critical Appraisal (or assessment of study quality) is required in order to avoid over- or under-reliance of certain findings, which could potentially distort the synthesis [25]. It is generally agreed that the methods developed for assessing quantitative research are inappropriate for reviewing qualitative research [26,27] yet to-date no common ground has been established regarding the most useful of these [11].

This review utilized the quality assessment framework published by the UK National Centre for Social Research [28], which was applied to each of the eight articles. Although the application of this was based upon the authors' subjective judgement to some extent, it was made more transparent through the use of an appraisal system. A grade of A-D was allocated to each of 18 appraisal questions based on the following system: A (No or few flaws), B (Some flaws), C (Significant flaws) and D (Untrustworthy). The coding was conducted by both authors independently, and disagreements were addressed through discussion. The grades were then converted to numbers and the mean was taken to generate an overall grade. The appraisal questions were therefore equally weighted in determining the overall grade.

Based on this appraisal system, six of the articles [13-17, 19] were allocated a grade B, one article [18] was allocated a grade C, and one article [20] was allocated a grade D. Despite the apparent flaws of some of the articles, all eight were included in the review for the following reasons: Firstly, it has been recommended that rather than using qualitative research tools to inform a decision of whether to include or exclude an article (as in the context of

quantitative research), they are best used as a process of exploration and interpretation [11,28]. Secondly, it was felt that, despite their flaws, each article could contribute something of value to the review.

1.4.4 Stage 4: Synthesis of findings

A diverse range of methods for synthesizing qualitative research findings have been used by researchers, but there is no consensus on the most appropriate of these [11,29]. This review utilized an inductive secondary thematic analysis approach. This approach was chosen because it could be used to conduct an interpretative synthesis, whilst still preserving the individual integrity of individual studies by remaining “close” to the primary data. Other reviews using secondary thematic analysis have been successfully able to achieve this balance (e.g. see [23,30,31]).

It was decided what all sections of articles labeled “results” or “findings” would be classed as data and included in the overall synthesis [31]. The reviewed articles were first read independently, and salient points from each article were listed and similar points, within and between articles, were clubbed to form a theme. A suitable phrase that best described the theme was created as the thematic label. This is not an exact science, but only a method to condense information into meaning units. Therefore, there may be overlaps between some themes, but these were retained as distinct to permit an in-depth examination of the data.

1.5 **RESULTS**

The general characteristics of the reviewed articles and critical appraisal are presented in Tables 1 and 2 respectively.

1.5.1 **Aims of included studies**

It was felt that all eight articles offered a clear statement of the study aims and purpose. Whilst it was felt that six articles adequately addressed their original aims via their findings and conclusions (13-17, 19), in two articles the experiences of HCPs were not explored in enough depth to achieve these aims [18, 20]. Despite the differences in specific aims across the eight articles, all explored HCPs' perceived barriers to discussing sexuality issues with service-users, and five studies explicitly explored how these barriers could be overcome [13–15,17,19].

1.5.2 **Samples**

Together, the eight articles reported on data from a total of 181 HCPs working in primary care (n=57), cancer services (n=43), intellectual disabilities services (n=71), and in a Disability and Rehabilitation Team (DART) (n=10). Five articles provided a reasonable description of the sample composition [14–18], but three did not provide sufficient demographic information (i.e. the gender, age range, and/or roles of participants) [13,19,20].

Most articles described participants recruited through self-selected methods [13–17] (although some used purposeful sampling to maximize diversity [14–17]), and participants in the others were approached directly and asked to take part in the study [18-20]. Five articles considered how the sampling method used could create bias in terms of a possible over-representation of HCPs who have an interest in sexuality issues, or of those who are already doing good work in the area [13–16]. However, the findings did not demonstrate wide-scale good practice, and therefore it seems unlikely that the samples were positively skewed [13]. Other limitations of achieved sample coverage were also acknowledged, such as an over-representation of some Primary Care Trusts

Table 1. General characteristics of the included studies

| Study Reference | Aims | Sample Size | Sample Composition | Location | Data Collection Method | Data Analysis Method | Key Findings |
|--|---|-------------|--|--|----------------------------|---|--|
| Abbott & Howarth, 2007 [13] | To explore how able, or willing, staff are to address sexuality issues in intellectual disability services. | N=71 | Managers and support staff in intellectual disability services | 20 services in UK England=11 Scotland=4 Wales=1 Northern Ireland=4 | Semi-structured interviews | Grounded Theory Constant comparative method (Glaser & Strauss, 1967) | The majority of staff said that they did not feel confident working with intellectual disabilities in the area of sexuality and relationships, especially those that are gay, lesbian or bisexual. Barriers: concern about intrusiveness/appropriateness of the topic, lack of confidence or willingness to engage in the work, lack of policy and training, and concerns about the reactions of others (particularly parents/carers). Facilitators: policy guidance, education and training. |
| Gott, Galena, Hinchliff & Eiford, 2004 [14] | To identify the barriers perceived by GPs and practice nurses to inhibit discussion of sexual health issues in primary care and explore strategies to improve communication in this area. | N=57 | 22 GPs (13 male and 9 female aged 34-57). 35 practice nurses (35 female aged 32-60) | Sheffield, England, UK | Semi-structured interviews | Grounded Theory (Strauss & Corbin, 1990) Assisted by QSR NUD*IST | The term "can of worms" summarised participants beliefs that sexually related issues are problematic. Barriers: sensitivity and complexity of the topic, constraints of time and expertise, discussing sexual health with patients of the opposite gender, black and ethnic minority groups, middle-aged & older patients, and non-heterosexual patients. Facilitators: training, providing patient information and expanding the role of the practice nurse. However, limitations of these approaches were also identified. |
| Gott, Hinchliff & Galena, 2004 [15] | To explore how GPs perceive and manage later life sexual health problems. | N=22 | GPs (13 male and 9 female aged 34-57) | Sheffield, England, UK | Semi-structured interviews | Grounded Theory National Centre for Social Research "Framework" approach (Ritchie & Spencer, 1994) | GPs did not address sexual health proactively with older people. Barriers: sexual health was equated with younger people & not seen as a legitimate topic for discussion with older people. Many beliefs were based on stereotyped views of ageing and sexuality, rather than personal experiences of individual patients. Facilitators: education and training |
| Hinchliff, Gott & Galena, 2004 [16] | To explore the barriers related to gender that GPs face when discussing sexual health matters in primary care consultations. | N=22 | GPs (13 male and 9 female aged 34-57) | Sheffield, England, UK | Semi-structured interviews | Thematic Analysis Assisted by QSR NUD*IST | GPs were virtually unanimous in believing that patients preferred to see a same-sex GP regarding sexual health. Barriers: becoming "de-skilled" in dealing with sexual matters of opposite sex patients. Discussion may also be hindered if the patient is male, as reproductive issues provided an appropriate context to asking about sexual health. |

| | | | | | | | |
|---|---|------|---|------------------------|--|--|---|
| Hinchliff, Gott & Galena, 2005 [17] | To explore the difficulties GPs experience when dealing with the sexual health care of gay and lesbian patients. | N=22 | GPs (13 male and 9 female aged 34-57) | Sheffield, England, UK | Semi-structured interviews | Thematic Analysis Assisted by QSR NUD*IST | Non-heterosexual orientation could form a barrier to talking about sexual health matters for almost half of the sample. Barriers: ignorance of lesbian and gay lifestyles and sexual practices, concerns about appropriate language to use, and assumptions about the nature of gay men's relationships. Facilitators: training, taking a proactive role during consultations, not making assumptions about the patients' sexual orientation, and having a non-discriminatory policy. |
| Stead, Brown, Fallowfield & Selby, 2004 [18] | To identify the level of information currently provided on sexual issues in ovarian cancer, the opinions of HCPs about sexual issues, and any training needs of medical staff. | N=58 | 27 doctors and 16 nurses treating women with ovarian cancer. 15 women with ovarian cancer across 3 hospitals | Leeds, England, UK | Semi-structured interviews | Frequency counts and qualitative comments summarised | The majority of staff thought that most women with ovarian cancer would experience a sexual problem, but only a quarter of doctors and a fifth of nurses actually discussed sexual issues with the women. Barriers: the belief amongst HCPs that it is not their responsibility to discuss sexual issues, embarrassment, lack of knowledge and experience, and lack of resources to provide the support if needed. |
| Rubin, 2005 [19] | To explore the reasons given by a Disability and Rehabilitation Team (DART) for perceived difficulties in discussing sexual problems with male patients with Multiple Sclerosis (MS), and to compare them with a group of patients. | N=10 | DART comprising nurses, occupational therapists, speech and language therapists and a physiotherapist) | UK | Focus group (semi-structured interview schedule) | Grounded Theory (Strauss & Corbin, 1990) | Barriers: worry about intrusiveness, not having enough information to give to patients was perceived as embarrassing, and lack of training. Facilitators: Team members identified that nurses are the best people to deal with sexual issues. |
| Stead, Brown & Fallowfield, 2002 [20] | To explore the psychosexual effects of ovarian cancer, and the level of communication between women and HCPs about sexual issues. | N=58 | 27 doctors and 16 nurses treating women with ovarian cancer. 15 women with ovarian cancer across 3 hospitals | Leeds, England, UK | Semi-structured interviews | Grounded Theory (Strauss & Corbin, 1990) | All but one health professional thought that medical staff should discuss psychosexual issues; however only four clinicians and five nurses did so. Barriers: the belief amongst HCPs that it is not their responsibility to discuss sexual issues, embarrassment, inexperience, lack of time, and lack of knowledge about the effects of ovarian cancer on sexual functioning. |

Table 2 Critical appraisal of the included studies

| | Appraisal Question | Study Ref. | | | | | | | |
|----|--|------------|----------|----------|----------|----------|----------|----------|----------|
| | | [13] | [14] | [15] | [16] | [17] | [18] | [19] | [20] |
| 1. | How credible are the findings? | B | B | B | B | B | C | B | D |
| 2 | How has knowledge/ understanding been extended by the research? | B | B | B | B | B | B | B | C |
| 3 | How well does the evaluation address its original aims and purpose? | B | A | A | A | A | C | A | D |
| 4 | Scope for drawing wider inference – how well is this explained? | B | B | C | C | B | B | B | D |
| 5 | How clear is the basis of evaluative appraisal? | B | B | C | D | C | D | A | C |
| 6 | How defensible is the research design? | B | C | C | C | C | C | A | D |
| 7 | How well defended is the sample design/ target selection of cases/documents? | B | B | B | B | B | C | C | D |
| 8 | Sample composition/case inclusion – how well is the eventual coverage described? | C | B | B | B | A | B | C | C |
| 9 | How well was the data collection carried out? | B | B | C | B | B | D | B | B |
| 10 | How well has the approach to, and formulation of, the analysis been conveyed? | C | C | C | C | C | D | C | D |
| 11 | Contexts of data sources – how well are they retained and portrayed? | C | B | B | C | C | D | B | D |
| 12 | How well has diversity of perspective and content been explored? | B | B | B | C | B | D | B | D |
| 13 | How well has detail, depth and complexity (i.e. richness) of the data been conveyed? | B | B | B | B | B | D | B | D |
| 14 | How clear are the links between data, interpretation and conclusions – i.e. how well can the route to any conclusions be seen? | B | B | B | C | B | C | C | D |
| 15 | How clear and coherent is the reporting? | B | A | B | C | B | B | B | D |
| 16 | How clear are the assumptions/theoretical perspectives/values that have shaped the form and output of the evaluation? | D | D | D | C | C | D | D | D |
| 17 | What evidence is there of attention to ethical issues? | D | B | C | B | B | C | A | C |
| 18 | How adequately has the research process been documented? | C | B | B | B | B | B | B | D |
| | Overall grade | B | B | B | B | B | C | B | D |

Key: A) No or few flaws B) Some flaws C) Significant flaws D) Untrustworthy.

[15,17] and small sample sizes [18,19], both of which could limit the generalizability of the findings to other healthcare settings and staff populations. Only one article reflected on the possible reasons for non-participation in the study; General Practitioners (GPs) reported a lack of time [17].

1.5.3 Study location

In one article the location could not be determined [19], most likely for confidentiality reasons given that the data was collected from one multi-disciplinary team. One article reports on data collected across a range of 20 intellectual disability services in the UK [13], which makes drawing wider inference from the findings more feasible. The other articles report on data collected in Sheffield [14–17] and Leeds [18,20], indicating that there is clearly an overrepresentation of data drawn from Yorkshire, England.

1.5.4 Ethical considerations

Some consideration of ethical issues was evident in all but one article [14–20]. However, in one of these it was simply an acknowledgement that local ethical approval had been granted [20]. The majority of articles considered issues of confidentiality and anonymity [14–17,19], and informed consent [16–19]. Only one article explicitly stated that transcripts were sent to participants for verification [19], which is beneficial to improve the credibility and face validity of the findings. In the other articles it is not known how data was presented to participants or if member checking occurred.

1.5.5 Data collection

Seven articles (i.e. three out of four studies) report on data collected using face-to-face semi-structured interviews with HCPs, the other using a semi-structured focus-group method [19]. It was felt that only two articles adequately justified their reason for choosing their method [13,19]. Two articles reported that researchers made field notes [14,19], however, only the latter article made

reference to these in the findings section, so it is unclear how they were used to aid analysis in the other.

Five articles contained some information about the content of the topic guide [13,14,16,17,19], which was useful as it made the link between the data collection and analysis more transparent. In one article the content of the topic guide was vague [19], but it is important to consider that the content of the interview itself may have been left deliberately broad. Two articles did not disclose the content of the topic guide at all [15,20], which made it difficult to assess whether the study was adequately designed to address the original aims of the research. Six articles reported using audiotape [13,14,16,17,19,20], and half of the articles reported that the raw data was then transcribed verbatim [14,16,17,20]. In the other four articles, the method for preserving raw data was not stated.

1.5.6 Data analysis

All but one article [18] stated their underlying theoretical framework; five articles claimed to use a Grounded Theory approach [13–15,19,20] and two articles claimed to use Thematic Analysis [16,17]. The other article, whilst using a qualitative method of data collection, did not use a recognized method of qualitative analysis [18]. This article simply stated that “qualitative comments were summarised” and the analysis appeared to be largely quantitative. Five articles reported that coding was carried out by multiple analysts [13–15,17,19], which has the potential to enhance the credibility of the findings. Four of these five articles acknowledged that any discrepancies were discussed until consensus was reached [14,15,17,19] and in the other article [13] it is not known whether there were any discrepancies between the two researchers or how they were resolved.

It was felt that none of the articles justified their approach or explained the analysis process in adequate depth, and as a result it was often difficult to understand how the themes were derived. Whilst this did not affect the

feasibility of synthesizing the findings from the articles, it did mean that it was not possible to explore the impact of theoretical framework on the interpretation. Furthermore, none of the articles reported on whether saturation of data was achieved, and authors in only two articles critically considered their role as researcher and how this may have impacted on the data collection and analysis process [16,17].

1.5.7 Reporting

It was evident that the majority of articles did include original data in their reporting of the findings in the form of direct quotations from participants [13–17,19]. This was advantageous as it allowed the subjective experiences of the participants to be represented to a reasonable degree. It also meant that a distinction could be made between the original data and the authors' interpretation. This may have been difficult otherwise, particularly as most authors adopted a descriptive writing style. In the two articles which had undertaken relatively simple qualitative analysis [18,20], it could not be determined at all what was original data and what was the researchers' analytical interpretation.

It is important to consider that examples of good practice in terms of HCPs discussing sexuality with service-users appeared to be somewhat under-represented in the articles, and it is unclear whether this was a reflection of the content of the original data, or of possible bias in the information that the authors chose to present. In one article [16], 9 out of the 22 GPs interviewed said that they felt comfortable talking about sexual matters in consultations, but this was not expanded upon. Further analysis of the interviews of these participants may have been useful to gain an alternative perspective on the barriers and facilitators to having such discussions about sexuality

1.5.8 Synthesis of themes

The review found that majority of HCPs included did consider it important to discuss sexuality [14,15,18-20]. However, despite this apparently widespread recognition, the main theme across all of the included articles was that sexuality is not routinely discussed in healthcare services. Nineteen main interconnected themes were drawn out from the secondary thematic analysis related to the reasons why HCPs do, or do not, initiate discussions with service-users (i.e. the barriers and facilitators). These themes are presented in Table 3, and the most common are discussed below.

HCPs in three articles referred to discussing sexuality as opening “a can of worms” or “Pandora’s box” [14,18,19]. This analogy was used to express their feelings about addressing a sensitive and complex issue within the time and resource limitations of the organization in which they work [14]. Indeed, HCPs in six articles identified that organizational factors (such as limited time, resources, and lack of privacy) can prevent them from having such discussions [14–17,19,20]. The difficulty appeared to be not with initiating the discussion *per se*, but that “*once you’ve opened up that can of worms, you’ve got to follow it through*” (Practice Nurse: aged 40-49) [14]. Some HCPs questioned whether it was actually fair to the patient to broach a subject they felt ill-equipped to deal with [17,19]:

“If you broach areas which are potentially incredibly complicated and insoluble and maybe you’re outside the ability to do anything about it anyway and then what good does it do to you or them?” (Male GP: aged 40-49) [14]

This reflects some HCPs’ belief that they do not have the knowledge and expertise to deal with the complexities of sexual health issues, a theme identified in all eight articles. HCPs in seven articles identified education and training as a potential facilitator to help them to overcome this barrier [13–19]. Staff that had attended training on sexuality issues commented that they found it helpful and were positive about it [17].

Table 3. Themes, and the articles which endorse them

| Theme | Study Ref. | | | | | | | |
|--|------------|------|------|------|------|------|------|------|
| | [13] | [14] | [15] | [16] | [17] | [18] | [19] | [20] |
| Fear of opening up a can of worms | - | + | - | - | - | + | + | - |
| Worry about causing offence | + | + | + | - | + | + | + | - |
| Concern about the reactions of parents/residential staff | + | - | - | - | - | - | - | - |
| The service-user should raise it first | + | + | + | - | - | + | + | + |
| Personal discomfort | - | + | + | + | + | + | + | + |
| Language barriers | - | + | - | - | - | - | - | - |
| Service-user may sexualise the consultation | - | + | - | + | - | - | - | - |
| Concern about own knowledge and abilities | + | + | + | + | + | + | + | + |
| Lack of training | + | + | + | + | + | + | + | - |
| Lack of recent experience | + | + | - | + | + | - | - | - |
| Lack of time and resources | - | + | + | + | + | - | + | + |
| Lack of written information | + | + | - | - | + | + | + | - |
| Lack of policy guidance | + | - | - | - | + | - | - | - |
| Do not consider it their responsibility | - | + | - | + | - | + | + | + |
| Lack of communication between professionals | - | - | - | - | - | + | + | - |
| Not giving "permission" to raise the issue | - | - | + | - | + | + | - | - |
| Assume it is not an important issue | - | + | + | - | - | + | + | + |
| Lack of awareness of range of sexual issues | - | + | + | + | + | - | + | + |
| Assuming the cause of the sexual issue | + | - | - | + | - | - | - | - |

Key: + Theme present - Theme not present

HCPs highlighted that any training which is offered needs to be more inclusive of minority service-user populations; HCPs reported that sexuality issues in relation to intellectual disabilities [13], gay, lesbian and bisexual issues [14,17], and older people [14,15]⁶ were only very briefly covered in their curriculum, if not absent altogether. However, HCPs in four articles raised concerns about whether attending training is actually feasible given the competing pressures of limited time and resources [13,14,16,17]:

“There’s only a certain amount in the training budget and they’ll pick out what really needs doing and move the other stuff to the side”[13].

HCPs also attributed their lack of knowledge to a lack of recent experience, meaning they were not always up to date with the latest developments in the field [13,14,16,17]. For example, GPs and practice nurses reported that they have become “rusty” in managing the sexual issues of opposite gender patients due to seeing more patients of the same sex as themselves [14,16].

Six articles reported on the belief amongst HCPs that raising the issue of sexuality could be perceived as intrusive or inappropriate, which led to some wondering whether service-users would perceive it as a legitimate topic for discussion [13–15,17–19]. Again, this theme was particularly marked in relation to particular patient groups; HCPs in primary care had preconceived ideas that sex is less openly discussed by people from black and minority ethnic groups, and by older people [14,15].

There were mixed reports on whether these concerns of causing offence were based on reality or not. Two articles reported that GPs could not recall any occasions of causing offence by raising such issues [14,15], suggesting that their decision not to initiate discussions are based on pre-existing beliefs and stereotypes of how they *think* people will respond rather than direct personal experiences. Indeed, one GP reported feeling surprised that Pakistani women

⁶ Within the context of this study, HCPs categorised older people as people in their 40s or over. In other studies, the age of older participants was not reported but they were termed ‘older’. To remain faithful to these studies, throughout this review we too report these participants as being ‘older’.

were ready to discuss sex [14]. However, in another study one member of a DART commented that “*several of us had examples where people had told us to mind our own business*”[19].

Related to this theme, six articles reported that healthcare professionals tend to take the lead from the service-user rather than initiating discussions themselves [13–15,18-20]. HCPs therefore considered it important that service-users feel comfortable enough to raise sexual issues themselves [15,17,19]. Providing an environment which grants permission to discuss sexuality issues can also be achieved at the organizational level; for example, HCPs in five articles reported a general lack of written information on sexuality and sexual dysfunction [13,14,16–18] which inhibited service-user initiated discussions, and believed that having leaflets/posters available could facilitate discussion [13,18,19]. However, others predicted that patients would feel too embarrassed to pick up information in a waiting room, and highlighted that if information is available, someone has to be available to answer any questions that it may raise for patients [14]. In addition, HCPs in two articles reported that the introduction of policy guidance would serve the purpose of giving work in the area of sexuality legitimacy [13], and encourage service-users to be open about sexuality issues [17].

In establishing this environment, HCPs may also need to overcome their own feelings about discussing sexuality issues. All but one article [13] reported on HCPs’ feelings of personal embarrassment/discomfort when discussing sexuality with service-users. In addition, field notes from one study also indicated that HCPs were feeling embarrassed during the focus group [20]. It may also have been useful for other studies to use field notes in the same way.

Again, this theme of personal discomfort discussed in relation to particular patient groups. For example, GPs in two articles reported feeling less comfortable discussing sexuality issues with opposite-gender patients, which was partly due to concerns that they may “sexualise the consultation” [14,16]. However, it is important to note that gender was not cited as a barrier by the majority of participants across the articles.

Some attitudes towards discussing sexuality with particular patient groups were more negative: for example, one GP referred to older peoples' sexuality as "distasteful" [15], and another admitted to finding some non-heterosexual acts "personally repugnant" [17]. One HCP also questioned the ethics of prescribing Viagra to gay men:

"I think it's a slightly inappropriate use of resources really, but it's probably just my prejudices, I'm prepared to admit that...particularly if they're not in a stable relationship, I don't see it's appropriate" (Male GP, aged 50 years) [17].

However, it is important to note that these ageist and homophobic viewpoints did not appear to be shared by the majority of HCPs. Most were keen to increase their knowledge of non-heterosexual sexual practices and lifestyles [17] and to reconcile their own views about non-heterosexuality [14].

HCPs in five articles expressed views that sexuality-related issues were outside of their responsibility or professional role [14,16,18-20]. For example, GPs expressed concerns about whether sexual health should actually be considered a "medical" issue or not [14]. In the focus group study [19] there was unanimous agreement that it should be the nurse's role. However, nurses expressed concerns about "opening up" such issues and then not being able to refer on to specialist services or prescribe medication [14]. Related to this, two articles highlighted that strategies are needed to improve communication between HCPs to decide who will talk about sexuality and when [18,19], although the latter article used a relatively simple analysis and did not explore this in detail.

Five articles reported on a lack of awareness amongst HCPs that sexual issues are an important issue [14,15,18-20]. For example, two articles reported that some HCPs working with women with ovarian cancer had never thought about it before [18-20]. Of the participants that *were* aware of the impact of ovarian cancer on sexual functioning, only a few out of the wide range of possible problems were named [18]. Other articles also indicated that HCPs associate

sexuality and sexual health with a relatively small number of issues [14-17,19,20];

“You automatically think of risky behaviour. You think of contraception and you think young people” (female GP: aged 50-59) [15].

HCPs in three articles acknowledged that they tended to think of sex as less relevant and less important to older people [14,15,18]; an attitude which could form a barrier to addressing sexual issues with people of an older cohort. In addition, HCPs working in services for people with intellectual disabilities expressed the view that service-users are “confused” about their sexual identity, and that same-sex sexual encounters are often an expression of a sexual need in an environment with little choices, rather than an expression of a non-heterosexual orientation [13]. By some HCPs holding assumptions such as these ones, it could mean that that some service-users’ issues, particularly those of gender and sexual minorities, are overlooked.

1.6 DISCUSSION

The synthesis supports previous quantitative research findings that HCPs do not routinely raise issues of sexuality with service-users, and similar barriers were identified [5–7]. A model has been developed to represent the main barriers and facilitators perceived by HCPs to discussing issues of sexuality (Figure 1). The components of the model include organizational, structural, and personal factors. The themes are considered to be intricately linked and have a combined effect on HCPs decision whether to initiate discussions of sexuality with service-users. In addition, the barriers seem to be exacerbated when HCPs work with certain service-user populations; those of the opposite gender, black and minority ethnic groups, older service-users, non-heterosexual service-users, and those with intellectual disabilities.

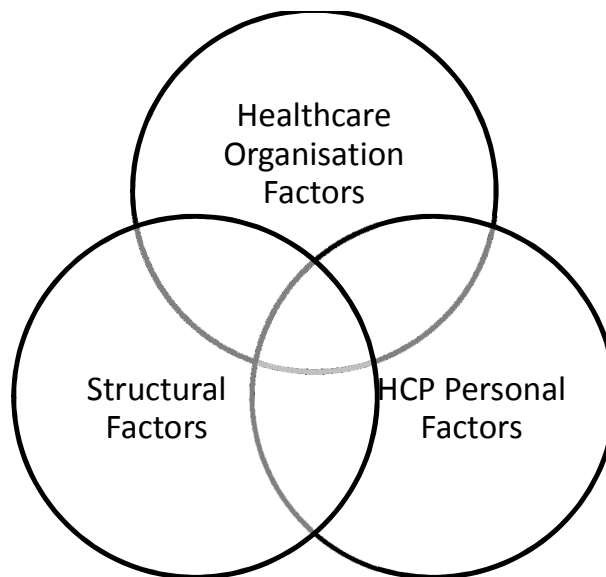


Figure 1. Factors influencing healthcare professionals' discussions of sexuality with service-users.

Factors within the organization seemed to determine how and whether HCPs discussed issues of sexuality with service users. HCPs identified that a lack of time, resources, policy, and training can prevent them from “opening up the can of worms”. Indeed, previous research has indicated that training in sexual issues can facilitate increased comfort in having discussions [32,33]. In addition, an organization’s shared values, norms, and practices are likely to guide the HCPs behavior.

Structural factors represent the economic, political, and organizational aspects of wider society over which HCPs have little personal control. Barriers such as lack of time, resources, and policy are likely to be influenced by the wider economic climate, current government incentives, and restrictions. In addition, the view that raising sexuality issues could be perceived as offensive, as well as the categorization of older people and people with intellectual disabilities as “asexual” is likely to be underpinned by wider societal images [34,35]. Furthermore, the dominant discourse in society that heterosexuality is the “norm” has dangerous implications as it serves to reinforce stereotypes that homosexuality is not “normal”.

Personal factors relate to the knowledge, motivation, and the personal attitudes of individual HCPs, which could work to impede or facilitate discussions. This is consistent with previous findings which suggest that increased knowledge [36] and more liberal sexual attitudes facilitate the discussion of sexual issues [33]. It is also important to note that these personal beliefs are likely to be underpinned by wider societal views, as well as personal upbringing and religious beliefs. In addition, HCPs’ interpretations of the concept of sexuality could act as a “filter” to whether, and which issues are raised.

Before considering the implications of this model and review in general, it is important to consider the limitations of this review. This was a relatively small systematic review based on eight articles. However, as some articles reported on findings from the same study, the review was only based on four unique studies. It may have been useful for the inclusion/exclusion criteria to be less stringent so that a greater number of articles could be included in the review (e.g. by including non-UK studies and those conducted over ten years ago).

However, issues such as sexuality are temporally and culturally determined, and widening the inclusion criteria would have made it difficult to meaningfully synthesize information.

The secondary thematic analysis methodology was useful for identifying whether the same themes had been identified across studies with different samples. However, this method is susceptible to imprecision because this approach only captures the themes that were (subjectively) determined by the authors of the reviewed articles to be of particular significance; failure to identify a theme does not mean that it does not exist.

Some of the limitations relate to the data from the primary studies themselves. For instance, in reporting information on the sample it would have been useful for more authors to have considered assessing reasons for non-participation, so that there is the potential for future research to increase the participation of currently under-represented groups. As most of the studies were conducted in Yorkshire, it is not known whether the attitudes and opinions of HCPs in this area differ significantly from elsewhere in the UK, which could limit the generalizability of the synthesis. In terms of the perceived utility of findings, all eight articles contained some reference to how the study could be utilized to enhance existing knowledge and understanding. All the authors considered how the findings have extended upon previously conducted research, and how the study could be used to improve healthcare practice. However, only one article considered how the study may have implications for the development of policy [13]. Two articles identify that future research is currently underway to expand upon the findings [15,19], but disappointingly none of the articles identify areas where future research is necessary. Only one article reflected on the possibility that presentation bias may have occurred during the interviews [15], that is, HCPs may not want to disclose information that could be perceived negatively. This is surprising considering that *all* of the studies required HCPs revealing rather personal information about their own attitudes and clinical practice.

This review highlights that further training needs to be available for all HCPs, which mirrors the recommendation made in the National Sexual Strategy for

Sexual Health and HIV [37]. Training should include psychosocial aspects of sexual issues to reduce the “overmedicalisation” of these concerns, and should be inclusive of a wide range of service-user populations. Training could also be used to help professionals to recognize and address their own “deep rooted” beliefs and presumptions about sexuality, which are likely to be underpinned by wider societal discourses.

However, HCPs questioned the feasibility of implementing such training programs, namely due to time and resources. This suggests that interventions need to focus not only on the HCPs themselves, but also on the wider healthcare context in which they work. Unfortunately in the current economic and political climate it may be these factors which are more difficult to overcome. A number of other facilitators were suggested, for example, having written information available and the development of policy at a structural level could be a proactive way of constructing an environment which grants permission for service-users to raise sexuality issues. It would be useful for future research to evaluate the effects of the above interventions.

Finally, only one article in the review explored how the level of communication between HCPs could work to impede or facilitate discussions of sexuality [19]. Interestingly this article was unique in that it was the only study exploring the experiences of a multi-disciplinary team, rather than individual HCPs. Currently there are no other studies with which to make a comparison, and therefore it would be useful for future research to examine whether this theme is transferable to other teams.

1.7 CONCLUSIONS

This review of eight articles indicated that although the subject of sexuality is not routinely addressed in healthcare services, HCPs did believe that it should be. A number of barriers have been identified, which were particularly marked in relation to the sexuality of black and minority ethnic groups, people with intellectual disabilities, and with older and non-heterosexual service-users. Potential strategies (facilitators) to overcome these barriers are also discussed, such as training, policy development, having written information available for service-users, and communication between professionals. However, limitations of implementing these were also identified. Interventions to improve the extent to which service-users' sexuality issues are addressed in healthcare services need to take structural, organizational and personal factors into consideration.

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Journal Paper

2.0

JOURNAL PAPER

Talking about sex after TBI: Perceptions and Experiences of Multidisciplinary Rehabilitation Professionals

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2.1

ABSTRACT

Purpose: Research indicates that although 50-60% of people who have had a traumatic brain injury (TBI) experience changes in sexual functioning, sexuality issues remain largely unaddressed in rehabilitation. This study aimed to explore rehabilitation professionals' perceptions and experiences of discussing sexuality with service-users who have had a TBI.

Method: Purposeful sampling was used to recruit 24 participants from two local National Health Service trusts and from a national charity. Four focus groups were conducted with pre-existing groups of professionals, using a semi-structured interview schedule. Focus group data were transcribed verbatim and analysed using thematic analysis.

Results: Six main themes were derived from the analysis: 1) Sexuality after TBI is a specialist issue; 2) Sexuality is a sensitive subject; 3) Practicalities of discussing sexuality; 4) Roles and responsibilities; 5) Dilemmas about risk and vulnerabilities; and 6) Organisational and structural issues.

Conclusions: Our findings suggest that a more proactive approach to addressing sexuality issues be taken by incorporating sexuality into

assessments, and by having sexuality information available for service-users. Support for professionals is also needed in the form of the development of policy, on-going training, and supervision.

2.2

IMPLICATIONS FOR REHABILITATION

- Rehabilitation professionals find it difficult to deal with issues of sexuality following TBI, and the reasons for this are complex and interrelated.
- To provide holistic care, a more proactive approach to addressing sexuality issues should be taken. Professionals do not need to be an expert in sexual issues to open dialogue.
- Sexuality discussions should be incorporated into assessments, and written information should be available for service-users. Further training for professionals and organisational policy change is sometimes required to effectively deal with sexuality issues.

2.3 INTRODUCTION

Sexuality has been defined as the way that people experience themselves and each other as sexual beings [1], encompassing sexual activity, sexual orientation, gender identity and roles, eroticism, pleasure, intimacy, and reproduction [2]. Sexual wellbeing is increasingly being considered as an integral component of the total well-being of a person, for example, it is highlighted as a component of healthcare in the *International Classification of Functioning, Disability and Health* (ICF) [3], and is also referred to in the Department of Health's *White Paper: Healthy Lives, Healthy People* [4]. Sexual disturbances and dysfunction can cause frustration, anxiety, depression, and affect overall quality of life for both the patient and their partners [5] [see Extended paper: 3.1.1.1 The significance of sexuality].

A traumatic brain injury (TBI) occurs when an outside force causes temporary or permanent damage to the brain [see Extended paper: 3.1.1.2 Traumatic brain injury]. For individuals with TBI, disruption to sexuality has been believed to be 'more the rule than the exception' [6, p.1]. More formal findings have indicated that 50-60% of people report some level of disruption to sexual function post-TBI [7–10]. The reasons for changes in sexuality are complex and multifaceted, but TBI has the potential to disrupt social and relationship skills, body image and self-esteem, behavioural control, libido and the physical capacity to perform sexually [9–13]. Studies on post-TBI marital stability show divorce or separation rates ranging from 15% to 78% [14–20] [see Extended paper: 3.1.1.3 Sexuality after TBI, and 3.1.1.4 The biopsychosocial model of sexuality after TBI].

However, despite acknowledgement of wide spread disturbance in sexual functioning after TBI, research indicates that sexuality is a neglected area in TBI rehabilitation. For example, only small proportions (ranging from 0-11%) of people with TBI and their family members report that professionals made inquiries about whether they had any sexual concerns [9, 21]. As a consequence, many people with TBI may be suffering from undetected but treatable sexual problems [7].

A survey of 129 rehabilitation professionals [22] found that although 79% thought that sexuality ought to be addressed as part of the holistic care of persons with TBI, only 9% said that they address the topic on a regular basis. This highlights a conflict between staff ideology and practice regarding discussing and addressing service-users' sexuality, which has been supported by findings from the literature [23–25]. This is inadequate given that sexuality has been found to be predictive of overall adjustment to disability, self-esteem, and overall quality of life [13, 26] [see Extended paper: 3.1.1.5 Management of sexual problems after TBI in rehabilitation].

Research indicates that professionals may be reluctant to engage service-users in discussions about sexuality after TBI for a number of reasons, including personal embarrassment, lack of knowledge and training, lack of time and resources, believing it is not their responsibility, lack of policy, and the lack of a systematic approach to sexual rehabilitation post-TBI [23–25, 27, 28]. Furthermore, research has indicated that professionals tend to take a reactive approach, only addressing it if the service-user raises it first [22, 23] [see Extended Paper: 3.1.1.6 Professionals' perspective].

Previous research has largely been quantitative in nature, but researchers have suggested that qualitative research would provide a richer understanding of communication about sexual issues [24]. Indeed, only one qualitative study has investigated the subjective views of professionals about the issue [25]. However, with this study being conducted thirteen years ago in Israel, generalisability of the findings to current healthcare settings in the UK is potentially limited. Qualitative research in other healthcare settings (including a recent systemic review by Dyer and das Nair [29]), has reiterated some of the above reasons for lack of discussion regarding sexuality [See Extended paper: 3.1.1.7 Management of sexuality issues in other healthcare settings]. However, a deeper understanding of this specifically within TBI settings is required [see Extended paper: 3.1.2 Rationale for current study and 3.1.3 Research aim].

2.4 **METHOD**⁷

2.4.1 **Research design**

The research was conducted using a qualitative design, and the data was collected using focus groups with teams of rehabilitation professionals that already work together. Focus groups are useful for exploring people's knowledge, attitudes, and experiences [30]. Focus groups also offer the opportunity to observe how people interactively construct meanings: how opinions are formed, expressed, defended, and modified within the context of discussion and debate with others [31]. It was felt that data generated in the context of interaction between participants (as well as with the interviewer) offers a clear advantage over individual interviews [32] [See Extended paper: 3.2.1 Research design].

2.4.2 **Procedure**

A semi-structured interview schedule was developed to guide and open up dialogue about sexual issues post-TBI. This ensured that the participants across the different focus groups had the opportunity to discuss similar topics, but also had sufficient flexibility to allow the interviewer and participants to expand on pertinent areas. The questions were determined by the areas lacking in the literature, and aimed to explore perceptions and experiences of communication about patient sexuality, as well as considerations of what might help or hinder the communication process. Beyond this, a low moderator approach was adopted [see Appendix B: Focus group schedule].

Professionals who work with people with TBI were recruited either from the NHS (local TBI or neurorehabilitation teams), or from a national charity which supports people affected by brain injury. Initially, managers (or senior members of staff) were contacted about the study, who subsequently distributed

⁷ The full research procedure is depicted in Appendix A.

information about the study to professionals within their teams. A purposive sample of 24 participants (six males and 18 females) took part in one of four focus groups (FG1, FG2, FG3, FG4), stratified by the team in which they work. Focus groups contained five, seven, four and eight participants respectively. Participants were: occupational therapists (n=6), support workers (n=5), psychological therapists (n=3), physiotherapists (n=2), case managers (n=2), a medical doctor (n=1), and 'other' therapists (n=5)⁸. Their years of experience working with clients with a TBI ranged from one year to over 20 years [see Appendix C: Demographics of focus group participants].

Focus groups were held at the participants' team base between usual hours of working practice, and were facilitated by the first author (KD). The sessions lasted an average of 40 minutes (excluding time taken to complete consent forms and collect demographic information). The focus groups were audio-recorded to aid verbatim transcription. A modified Jeffersonian transcription style was employed⁹ [33] [see Appendix D: Transcript conventions]. As recommended in the literature [34, 35], field notes on non-verbal behaviour and group interactions were also made and incorporated into the transcripts [see Extended paper: 3.2.2 Procedure].

2.4.3 Data analysis

A thematic analysis was conducted at the manifest (i.e. surface) level, based on the six-stage process outlined by Braun and Clarke [36]. Transcriptions were initially read and re-read, noting down initial codes and categories in the right margin. Initial codes were then collated into themes [see Appendix H and I for a sample of analysis]. Finally, a thematic map was generated, incorporating main themes and subthemes [see Extended paper: Figure 5 for the thematic map,

⁸ Full job titles not provided to preserve anonymity.

⁹ (.) pause
- participant stopped mid-sentence
[overlapping speech
Italics laughter
Underline emphasis
((brackets)) additional researcher's comments.

and Appendix J for an earlier version]. The analysis was conducted within a critical-realist paradigm [see Extended paper: 3.2.5 Epistemological position]. [See Extended paper: 3.2.3 Data analysis].

2.4.4 Quality assurance measures

Faithful to the aims of qualitative research, we sought to ensure quality by establishing trustworthiness of the findings [37]. Both qualitative [37, 38] and thematic analysis specific [36] guidelines were followed. This study employed a number of techniques, including: 1) Researcher triangulation, by comparing independently coded transcripts and themes with the second author (RdN); 2) Maintaining an audit trail throughout the analytical process, to provide a transparent pathway for the researchers and others to follow the code and theme development; 3) Including verbatim quotations from participants, to enable the reader to assess the credibility of findings; and 4) Maintaining a reflective diary, to consider the impact of the interviewer upon the research from the conceptualisation stage through to the analysis and writing up the report. This was repeatedly scrutinised by the researcher to ensure that individual themes in the data were not under- or over-represented [see Extended paper: 3.2.4 Establishing quality].

2.4.5 Ethical considerations and approval

Ethical approval was obtained from the University of Lincoln's Ethics Committee, and from the Research and Development departments of the two participating NHS trusts [see Appendix E: Ethical approval documents¹⁰]. All participants were informed about the voluntary nature of participation and their right to decline and withdraw from the study [see Appendix F: Participant information sheet]. Written consent was obtained [see Appendix G: Participant consent form]. Participant identification codes are used throughout and

¹⁰ Please note that NHS R&D documents have been edited to preserve the confidentiality of the teams.

identifiable details removed to preserve anonymity [see Extended paper: 3.2.2.6 Ethical considerations and approval].

2.5 RESULTS

Altogether, over 1000 initial codes were identified from the focus group data, which were then analysed and grouped into main themes and subthemes, as shown in figure 2.

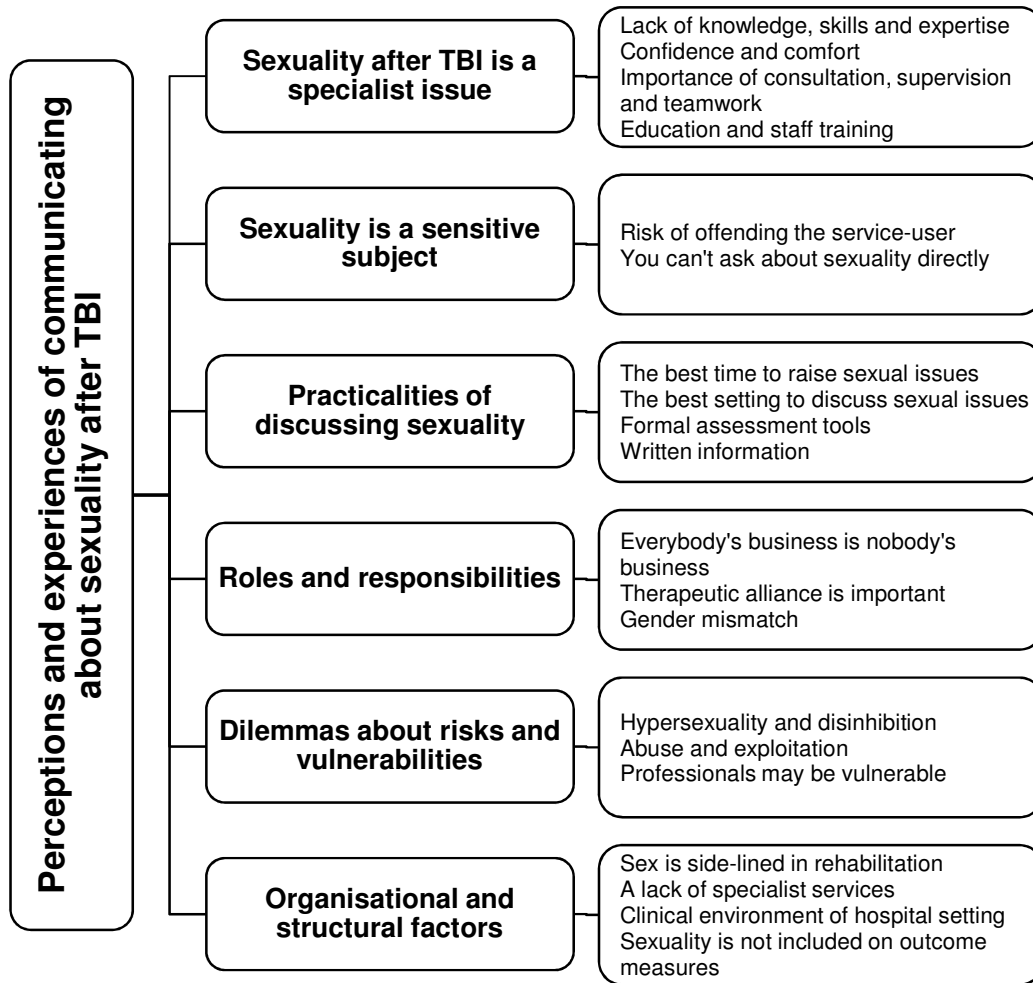


Figure 2. Overview of main themes and subthemes relating to professionals' perceptions and experiences of communicating about sexuality after TBI.

It is beyond the scope of this paper to address each of the main themes and subthemes in detail, however a brief overview of each of the main themes will be provided to highlight the specific issues raised by participants. For ease of reading, themes are displayed as being distinct from each other; however, themes often interlink, and, at times, overlap.

Sexuality after TBI is a specialist issue

This theme relates to the participants' perception that sexuality is a specialist subject which requires specialist knowledge, skills and training. At times a (perceived or actual) lack of knowledge, skills, and expertise prevented professionals from opening up discussions about sexuality, and also affected how they managed conversations when service-users raised the topic. For example, the participant in the extract below used a deflection technique by changing the subject:

P7:2¹¹ I've had a couple of service users bring the subject up of (.) sex and relationships (.) Erm, it's hard (.) I personally find it hard to talk about because I don't think I have the (.) proper knowledge to be able to explain it to that person...so yeah I just sort of skimmed over ((laughter from others)) the subject ((sounds of agreement from others)). Changed the subject

Participants highlighted that consultation, supervision and teamwork are all important in overcoming their lack of knowledge, skills and expertise. Several participants reflected on occasions where they had turned to other professionals (either within their team or externally) for advice or support with regards to managing sexual issues. For example, when reflecting on a personal experience of working with a service-user, one participant stated "the psychologist is working with me because it's too much for me to handle" (P1:3).

Participants also highlighted that further education and training would enable them to feel more equipped in dealing with sexual issues, although most made general references to the need for training, and did not specify any areas that training should cover. Some participants that were aware of training available through one particular organisation considered it insufficient:

¹¹ This code represents the participant ID. 'P7' is the participant number, and '2' is the focus group number. 'I' represents the interviewer.

peer-support to each other. Some participants commented that a standardised questionnaire or having written information leaflets available would help them to discuss sexual issues with service-users. For example, one participant felt that providing written information to service-users may create an environment which grants permission and 'empowers' them to raise sexual concerns:

P5:4 I don't think they have had this identified...even on the information leaflet, whether we need to give that information leaflet about the unit, like our unit and say - look, these are the aspects, but if you want to discuss it, feel free to discuss it. So at least they are empowered to say, this is something they can discuss...Because actually the patient, they are not aware they are allowed to discuss that with us

[See Extended paper: 3.3.1.3 Practicalities of discussing sexuality].

Roles and responsibilities

This theme relates to the dilemmas raised by professionals when considering who should address sexual issues with service-users with TBI. Most participants were against the allocation of a specific professional or discipline to address sexual issues given that it should be the service-users' decision who they decide to raise sexual issues with:

P5:1 I think then maybe it's the client's choice isn't it who's the most appropriate person, because they obviously choose who they want to tell about something so personal

However, one participant (P5:4) used the analogy of "everybody's business is nobody's business" to highlight the negative effects of not allocating a specific professional or discipline to discuss sexuality; i.e. when nobody is responsible for the task, everybody assumes that somebody else will do it, the implication being that nobody does it. The participant in the extract below also reflected on this:

Organisational and structural factors

This theme encapsulates participants' views about the factors within their organisation and beyond that help or hinder communication with regards to sexuality after TBI. Two participants used the analogy of "opening a can of worms" (P1:1; P5:4) to describe their feelings about opening up issues of sexuality when there is a lack of (or at least a lack of awareness of) available specialist services to refer service-users on to. The extract below illustrates how one participant proposes this theory, an idea which P2:1 had not considered previously:

- P1:1 I mean you might be asking a question with this, you know in this area, and erm and then you think what the hell *do I do with it (laughs)* ((laughter from others))...I mean I'm certainly aware that (.) our model is to deal with it ourselves or to refer on. And where do you refer on to? ...I don't view it ((sexuality)) as being particularly more difficult to address than any of the others, but it's just that issue about not really being sure about where you take it
- P2:1 I'd agree. Yeah, not thought of it like that before

Participants also reflected on how competing pressures of time and recourses mean that sexuality is side-lined in healthcare and rehabilitation settings for other, potentially more important, issues. For example:

- P1:3 ...we're so busy sorting out whether they can walk or talk or-, that we haven't got time a lot of the time. Y'know we- we- And it's almost-almost a luxury isn't it? Cos- ((sighs)) y'know, erm, I mean, does the NHS help you to have sex? (.) I don't know

In the above extract, the participant questioned whether the NHS is the appropriate context to facilitate sex. Participants in another focus group also discussed this subtheme of the side-lining of sexual issues in the context of the wider healthcare system:

- P2:1 And the whole wider context, it's just generally not (.) open. Well I think in the NHS it's sort of, do you know what I mean? It's sort of positive about this and positive about that, negative about smoking, positive about-...but if you think about it where have you actually seen a poster saying y'know sex is part of your life or whatever. It's just , sort of, not talked about. Eat your five a day and exercise five times a day¹³. Do you know what I'm saying it's not, it's just not-
- P5:1 It's just not out there [is it?
- P2:1 [Yeah it's not out there, that's it {P5 name}
- P1:1 It's not viewed as a necessity I guess. In terms of- well I suppose it's never an overall priority for healthcare is it? You don't see the government banging on about (.) targets for sex do you?

Finally, professionals across two focus groups pointed out that unlike other rehabilitation issues, sexuality is not included on formal measures of outcome (P5:4), and this places it as low priority within their organisation.

[See Extended paper: 3.3.1.6 Organisational and structural factors].

¹³ These refer to specific health campaigns promoted within many NHS settings.

2.6 DISCUSSION

Studies have shown that the rate of professionals that address sexual issues after TBI is low [9, 21–25]. This study presented a detailed exploration of professionals' experiences and views of discussing sexuality with service-users who have had a TBI. The main themes are discussed below with reference to the existing literature, and recommendations for future research are made.

The complexity of sexuality after TBI and training issues

Participants conceptualised sexuality after TBI as a complex issue that requires 'specialist' skills and expertise. Some professionals felt that training would facilitate communication about sexual issues, which supports findings from the literature [23–25, 28]. However, the qualitative methodology of the current study enabled further insight into the potential pitfalls of training: Firstly, some participants that were aware of training considered it to be of insufficient level. This is perhaps in line with findings from the literature which noted that only half of professionals that had attended sexuality training found that it had improved their practice, with 20% stating that it had been of no benefit to them at all [24]. Secondly, some participants advocated a more exposure-based approach to addressing sexuality. From a behavioural perspective, exposure can be thought of as counter-acting avoidance by becoming used to asking about sexuality, until it no longer provokes anxiety. This suggestion has not been highlighted in previous literature and therefore warrants further attention. Finally, participants placed high value on teamwork, supervision and consultation with other professionals in overcoming their lack of knowledge and expertise. Again, this theme warrants further attention.

Perceived topic sensitivity as a hindrance to discussing sexuality

The perceived sensitive and personal nature of the topic appeared to inhibit open dialogue between professionals and service-users after TBI. In particular, professionals were worried about offending service-users by raising sexual issues "too early" in the rehabilitation process. This theme is consistent with

previous research [25, 39–42]. However, research indicates that most service-users are *not* offended by discussion of their sexuality [43, 44] and do expect professionals to make inquiries about sexuality [45], but future research should be conducted specifically with people who have experienced a TBI.

Reactive vs. proactive ways of discussing sexuality

The findings indicated that professionals tended to wait until the service-user raised sexual issues first, a finding consistent with previous research [22, 23]. However, this reactive approach is considered problematic given the finding that service-users believe it to be the professionals' role to start the conversation [46], alongside evidence that service-users are concerned about raising the topic for fear of embarrassing the professional or being told that concerns are 'just in your head' [47]. Furthermore, service-users may be unaware of the link between TBI and sexual difficulties, thus deeming it to be irrelevant to the rehabilitation professional [7]. As a result, many sexual concerns could be going undetected.

Professionals highlighted that formal assessment tools and the provision of written information would enable them to address sexual issues more proactively, suggestions which have been made previously [7]. Professionals also highlighted the possibility of service-user groups/peer support to facilitate discussion about sexuality. Similarly, two-thirds of the professionals in Katz and Aloni's study [25] recommended group therapy as a preferred method for sexual rehabilitation post-TBI.

Roles and responsibilities

Professionals were reluctant to nominate specific professionals to discuss sexual issues with service-users, arguing that under ideal circumstances, the service-user should be able to choose whom he or she feels comfortable with for such discussions. This supports findings from the literature [24]. Davis and Taylor [48] have also indicated that addressing sexuality requires a multidisciplinary approach and therefore should not be the responsibility of a

single professional. However, there are two main limitations of this approach: Firstly, placing the onus on the service-user to raise sexual issues first is potentially problematic for the reasons highlighted earlier; and secondly, and as highlighted by the participants in one focus group, there is potential for members of the team to assume that other disciplines have addressed, or will address, sexual concerns. Indeed, Ducharme [49] found that service-users with spinal cord injury often left rehabilitation with no information about sexuality for this very reason.

Balancing risks and vulnerabilities with information-giving and support

Professionals highlighted concerns about service-users with TBI being sexually disinhibited, a link backed up by research [50–52]. Furthermore, professionals felt that service-users may be more vulnerable to abuse and exploitation as a result of their TBI. Although no studies have investigated the vulnerability of people with TBI specifically, evidence does suggest that people with disabilities more generally are more likely to experience physical, sexual and emotional abuse than any other group [53–55].

These issues should of course be given serious attention, however, it could be argued that this risk should not be used as a ‘smokescreen’ to deny service-users the opportunity to find a sexual identity and expression: “just as the labelling of disabled people as asexual is inappropriate, so too is an ‘overprotective’ atmosphere in which any evidence of sexuality is taboo” [46, p.436]. Moreover, it could be argued that while this is a risk, it is an inherent risk: i.e. there is no evidence that it emerges as the result of discussing sexuality in clinical or therapeutic encounters. In fact, blockage of age-appropriate and socially appropriate sexual information or experiences may actually serve to increase inappropriate sexual behaviour [56], as well as the incidence of sexual abuse [55].

Some professionals reflected on how sexual issues tend to only be addressed when they become a ‘problem for other people’, presumably in an attempt to reduce the future possibility of risky or inappropriate behaviour occurring.

Indeed, Miller has stated that “professionals frequently ignore, avoid, or quite innocently overlook the sexual needs of their patients until they begin to exhibit sexually inappropriate behaviour” [48, p.19].

Systemic and organisational hurdles to discussing sexuality

Dyer and das Nair’s [29] review of qualitative studies found that wider systemic factors such as limited time, resources and privacy can prevent discussions about sexuality from taking place, and indeed, professionals in the current study raised the importance of these issues. Professionals also highlighted that sexuality is side-lined within organisations, which supports findings from the literature [57–59]. Professionals’ perceptions that service-users share their focus on ‘walking and talking’ may well be congruent with service-users’ expectations, but further research is required to investigate this. However, research from other healthcare settings has shown that service-users do want and expect professionals to discuss sexual issues [60, 61].

Related to this, professionals highlighted that low priority is attributed to sexuality given that it is not included on formal measures of outcome. Indeed, sexuality is not included on the ‘UK *Functional Independence Measure*[™] *plus Functional Assessment Measure*’ (UK FIM+FAM) [62], which was specifically designed for use in brain injury [63], and has recently been widely introduced across rehabilitation settings. Furthermore, one professional highlighted that and as a result of this, there are no measurable consequences for not addressing sexual issues. This subtheme is significant as it has not been previously highlighted in the literature, warranting further attention in future research.

[See Extended paper: 3.4.1 Further interpretation of analysis and 3.4.4 Implications for future research].

2.6.1 Implications for practice, policy and training

Through their contact with service-users with a TBI, professionals have an important role in encouraging discussions about sexual concerns. Sexuality is a particularly important area to address given the high incidence of sexuality difficulties post-TBI, combined with the known importance of sexuality for overall wellbeing and quality of life. Furthermore, research has indicated that service-users do not generally discuss sexuality with family and friends [64].

We believe that the reactive approach taken by the majority of professionals is unsatisfactory, and a more proactive approach is recommended. This is also important in light of the Department of Health's ambition to strengthen the role of healthcare in the management of sexual health and wellbeing [65]. According to Herson et al. [66] "anyone in the helping professions, regardless of job title, can provide some level of sexuality information" (p. 149).

The PLISSIT model [67] has been used over the past 30 years by professionals working to address the sexual wellbeing of individuals with acquired disability and chronic illness [68]. The acronym PLISSIT signifies the four levels of intervention: Permission to discuss sexuality, provision of Limited Information regarding sexuality, Specific Suggestions regarding the person's sexual issues, and Intensive Therapy with an expert when needed.

Professionals are not expected to offer interventions at all levels, and are therefore not required to have 'specialist' skills. In some cases, it may be most appropriate for rehabilitation services to only screen for and identify concerns, before referring service-users on for more specialist assessment and/or treatment [67]. However, ensuring these individuals are identified and referred is an important first step in service provision. Indeed, Taylor and Davis [48, 68] later extended the model (the Ex-PLISSIT model), arguing that all levels should begin with explicit permission. At a minimum, this may involve letting service-users know that sexuality is a legitimate area for discussion in the rehabilitation setting.

As suggested by some participants, it would be beneficial for sexuality to be incorporated into routine assessments. This may involve asking service-users how their TBI has affected the way they see themselves as a male or female [61]. The question could then be followed by asking if they have any concerns about how their TBI has influenced their sexuality [69]. Having information resources readily available also contributes to an environment which grants service-users permission to think and talk about sexuality in relation to their TBI.

Getting sexuality issues into TBI rehabilitation is dependent upon much more than professionals' motivation: As highlighted by the participants, organisation and structural factors play an important role. Services need to be adequately staffed and resourced, and professionals need to receive adequate supervision. In services where this is not attainable, or where areas are outside of the scope of practice or expertise, it is important for agencies to develop links with specialist sexual health or therapy services to address these needs [see Extended paper: 3.4.3.1 Implications for Clinical Practice]. Furthermore, explicit policies and procedures are required to solidify a team approach on addressing and managing sexuality issues, and to provide consistency in the delivery of care. Policies should find an appropriate balance between enabling people with TBI to have their sexual rights and needs met, whilst reducing the risks of abuse and exploitation [see Extended paper: 3.4.3.3 Implications for policy].

Finally, taboos continue to represent an important challenge, and one which Celtek and Giraldi [46] believe can only be resolved through improved education at both undergraduate and postgraduate levels. This would help to raise awareness of the importance of sexuality for service-users in terms of general wellbeing and quality of life. Training should be available to all staff and should include: Information on how biological, psychological and social changes after TBI can impact on sexuality, the impact of medication, sexuality throughout the life-cycle, cultural differences, socially acceptable sexual expression, contraception, issues for lesbian, gay, bisexual and transgender TBI service-users, appropriate resources for sexual exploration (such as dating), identification and management of risk, as well as the law and policies that are in place within the specific organisation. Professionals are also likely to benefit

from ongoing in-service opportunities for open discussion, exploration and clarification of their values, attitudes, biases, and comfort levels in relation to sexuality [13, 22, 70, 71]. It would also be important for training programs to be evaluated in the future. [see Extended Paper: 3.4.3.2 Implications for training].

2.6.2 Limitations of the current study

The generalisability of the findings is potentially limited by the small homogenous sample and the researchers' subjective interpretation of the data. Whilst a number of quality assurance measures were put in place, rigour could have potentially been enhanced by sending transcripts or quotations to participants to check for accuracy and to comment on the researcher's interpretations. It is also important to consider how the focus group context may have impacted on the findings. For example, Sim [35] has suggested that focus groups may lead to the 'censoring' of opinions or experiences that differ from the majority view of the group, leading to a false impression of conformity amongst participants. However, a number of authors have suggested that focus groups can enhance openness and disclosure [30, 31] [see Extended Paper: 3.2.5 Strengths and limitations of the research].

2.7 CONCLUSIONS

Service-users who have had a TBI and their families are dependent upon professionals for assessment, guidance, education and support in dealing with sexual problems, yet sexuality has been a neglected area in TBI rehabilitation. This study explored the perceptions and experiences of rehabilitation professionals in discussing sexuality with service-users who have had a TBI, with similar barriers and facilitating factors being identified to those in previous literature.

This paper outlines a number of implications for clinical practice, training and the development of policy, in order that sexuality becomes accepted as an integral component of holistic rehabilitation. It is recommended that a more proactive approach to managing sexual issues is taken in clinical practice. However, without support for professionals in the form of the development of policy, on-going training, supervision, and adequate staffing, sexuality issues are in danger of being neglected.

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Extended Paper

3.0 EXTENDED PAPER

3.1 EXTENDED INTRODUCTION

This section expands on the journal paper by providing an overview of the relevant literature, which is then used to form a rationale for the current study. This section closes with the research aim.

3.1.1 BACKGROUND RESEARCH

3.1.1.1 The significance of sexuality

A review of the literature indicates that sexuality is a complex and ill-defined concept. Prior to the 1970s, research into sexuality concentrated on the biological aspects of sexual intercourse. Parker and Gagnon (1995) argued that this fitted with the positivist, scientific nature of research at this time. In the 1970s, a more inclusive definition of sexuality developed. Writers such as Gagnon and Simon (1973) and Foucault (1979) began to examine societal influences on sexuality, viewing it as a socially, culturally and historically specific concept which each individual experiences differently.

It is now widely recognised that sexuality is much more than just having sexual intercourse: It is now seen as crucial to the development of individual identity, or as Foucault (1979), famously wrote, it is “the truth of our being” (p. 7). Sexuality is now known to impact on all aspects of a person’s life, including physical, psychological and social health (Baker & Shears, 2010; Kazukauskas & Lam, 2009), and is now identified as a fundamental and natural need within everyone’s life regardless of age or physical state (Pangman & Sequire, 2000).

Survey studies in the normal population highlight the association between a satisfying sex life and overall quality of life (Kahneman, Krueger, Schkade, Schwarz, & Stone, 2004; Laumann et al., 2006; Marwick, 1999). Conversely, Sexual problems and disorders are known to affect overall happiness and

quality of life (Dolinska-Zygmunt & Nomejko, 2011; Laumann, Paik, & Rosen, 1999; Ventegodt, 1998).

3.1.1.2 Traumatic Brain Injury

A systemic review (of 23 studies) of the epidemiology of traumatic brain injury (TBI) in adults in Europe reported incidence rates of 150–300 per 100,000 per year, with the variation observed partially due to the differences in criteria used to define TBI or to identify patients (Tagliaferri, Compagnone, Korsic, Servadei, & Kraus, 2006). However, the majority of studies in this review are based on hospital data, and therefore it is probable that this figure is an underestimation given that many people may not seek medical attention after their injury. It has been reported that 40% of TBIs in Europe are caused by road traffic accidents, 37% are caused by falls, 7% are caused by violence or assault, and 16% by other causes. An association between alcohol involvement and TBI has also been reported (Tagliaferri et al., 2006).

TBI remains one of the most frequent causes of premature death and disability worldwide, and accounts for more productive years of life lost than cancer, cardiovascular disease, and HIV/AIDS combined (Zitnay et al., 2008). Those who do survive the initial cause of the TBI may experience significant temporary, prolonged or permanent neurological or neuropsychiatric problems, and may have significant cognitive, behavioural, physical, and communication needs, depending on the nature, location and severity of their injury (Turner-Stokes et al., 2007; Turner-Stokes, Nair, Sedki, Disler, & Wade, 2005). Following the initial stages of recovery, some patients will need to undergo a period of intensive inpatient rehabilitation to make the transition from hospital back into the community. Once in the community, attention typically turns more towards social integration, return to work and financial independence if possible (Turner-Stokes et al., 2005).

3.1.1.3 Sexuality after TBI

The many physical, cognitive, emotional and behavioural consequences of TBI can impact on various aspects of sexuality (Moreno, Arango Lasprilla, Gan, & McKerral, 2013). Overall research indicates that 50-60% of people with TBI report some level of disruption to sexual function (Kreuter, Dahllöf, Gudjonsson, Sullivan, & Siösteen, 1998; Kreutzer & Zasler, 1989; O'Carroll, Woodrow, & Maroun, 1991; Simpson, 2001), however, it is difficult to determine the actual incidence of sexual dysfunction after TBI, with the percentage of persons reporting decreased sexual functioning and/or satisfaction ranging from 14% to 93% (Sander et al., 2012). It is important to note that the majority of studies use convenience samples and outpatient clinic samples, which may limit the generalisability of the findings. Furthermore, some studies only included persons who are sexually active or those with partners, and some samples only included men as participants. In addition, many studies are limited by the use of non-standardised interviews as the primary outcome measure: The exception to this is the Derogatis Interview of Sexual Function [DISF] used by Sandel, Williams, Dellapietra, and Derogatis (1996), which allows comparison with a normative data sample.

Common changes include reduced sexual drive (Crowe & Ponsford, 1999; Kosteljanetz et al., 1981; Kreutzer & Zasler, 1989; Ponsford, 2003; Sabhesan & Natarajan, 1989), diminished or absent ability to achieve or maintain an erection (Kosteljanetz et al., 1981; Kreuter et al., 1998; Kreutzer & Zasler, 1989; Ponsford, 2003), reduced ability to achieve orgasm (Kreuter et al., 1998; Ponsford, 2003), diminished ability to form sexual images (Crowe & Ponsford, 1999), reduced or non-existent frequency of intercourse (Crowe & Ponsford, 1999; Garden, Bontke, & Hoffman, 1990; Kreuter et al., 1998; Kreutzer & Zasler, 1989; O'Carroll et al., 1991; Ponsford, 2003; Sabhesan & Natarajan, 1989), hypersexuality and/or sexual disinhibition (Miller, Cummings, McIntyre, Ebers, & Grode, 1986; Miller, 1994; Sabhesan & Natarajan, 1989).

3.1.1.4 The biopsychosocial model of sexuality after TBI

The reasons for changes in sexuality post-TBI are complex and multifaceted. A biopsychosocial model has been proposed (Gan, 2005; Moreno et al., 2013) to represent the interaction of neuropsychological and psychological effects, medical and physical issues and relationship factors (see figure 3).

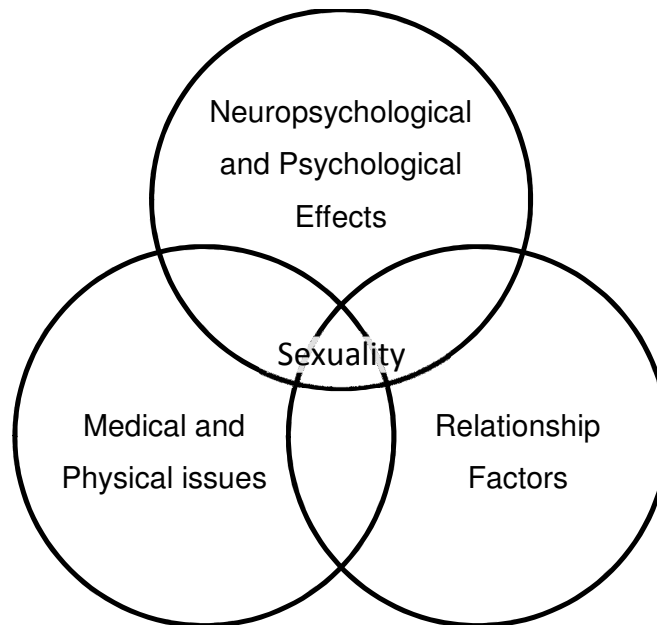


Figure 3. The biopsychosocial model of sexuality after TBI (Gan, 2005; Moreno et al., 2013)

Neuropsychological and psychological effects: Difficulties in attention, concentration, memory, communication, planning, organisation, initiation, and interest can be obstacles to sexuality and sexual interaction (Blackerby, 1990; Borgaro, Prigatano, Kwasnica, & Rexer, 2003; Bélanger, 2009). Psychosocial factors after TBI include decreased body image (Hibbard, Gordon, Flanagan, Haddad, & Labinsky, 2000), self-confidence (Crowe & Ponsford, 1999; Kreutzer & Zasler, 1989; Ponsford, 2003), sex appeal, and depression (Glenn, O’Neil-Pirozzi, Goldstein, Burke, & Jacob, 2001; Kreutzer & Zasler, 1989; Ponsford, 2003). Gaudet, Crethar, Burger, and Pulos (2001) found that compared to

controls, those who had experienced a TBI had more negative feelings about themselves, their sexuality and their relationships with others.

Medical and physical issues: The thalamus, the hippocampus, amygdala and the septal complex are all implicated in sexual stimulation (Horn & Zasler, 1990a), with temporal lobe dysfunction having been associated with decreased sexual and genital arousal (Horn & Zasler, 1990a). Furthermore, injuries to the hypothalamus may lead to irreversible loss of libido (Kosteljanetz et al., 1981). Physically, sensorimotor deficits and pain can adversely affect a person's ability to become aroused by sensory stimuli, and perform various movements involved in sexual activity (Moreno et al., 2013; Ponsford, 2003). Fatigue and sleep disorders can cause reduced sex drive and stamina for sexual activity (Ponsford, 2003). Furthermore, as more data are accumulated on the side effects of the various medications, it seems that every drug commonly used to treat survivors of TBI has side effects relating to sexual function (Aloni & Katz, 1999).

Relationship factors: Difficulties in social skills, verbal and non-verbal communication can create misunderstanding, stress, frustration and distance in relationships, all of which can affect intimacy and arousal (Horn & Zasler, 1990b; Kreutzer & Zasler, 1989; O'Carroll et al., 1991; Zasler, 1991). TBI survivors are often perceived by their partners to have changed personalities, which can evoke the feeling of living with a stranger (Aloni & Katz, 2003; Gosling & Oddy, 1999; Mauss-Clum & Ryan, 1981; Oddy, 2001). In a study by Maus-Clum and Ryan (1981), 42% of the wives surveyed reported that they had no sexual outlet, and 42% described themselves as "married without a husband". Gosling and Oddy (1999) found that increased dependence of the person with TBI led to some female partners viewing their role as 'maternal', thus inherently incompatible with an intimate relationship. Finally, some partners report being verbally abused, sexually coerced or threatened with physical violence (Gosling & Oddy, 1999; Mauss-Clum & Ryan, 1981). It is, however, important to note that these studies are limited by their small sample sizes and the dominance of non-injured female participants.

2.1.1.5 Management of sexuality after TBI in rehabilitation

Despite the many studies which report disturbance in sexuality and intimacy after TBI, as well as an impressive increase in the number of specialist TBI services and professionals working with this population, research indicates that sexual issues are infrequently addressed during the rehabilitation process (Elliott & Biever, 1996). For example, Zinn (1981) found that only 11% of patients on a rehabilitation unit reported that their doctors discussed sexuality with them. Kreuter et al (1998)'s study of 152 individuals treated in a rehabilitation department found that none had received sexual information or counselling after their TBI.

This is despite the fact that in 2001, the UK government published the National Sexual Health Strategy (Department of Health, 2001), which included the drive for more attention to be paid to the assessment of sexual and relationship needs, and was explicit about the services and treatments that people could expect to receive. However, it is important to note that this document does not make reference to specific service-user populations, such as those with disabilities and TBI. The *Rehabilitation from ABI: National clinical guidelines* (Royal College of Physicians [RCP] and British Society of Rehabilitation Medicine [BSRM], 2003) do recognise sexuality as an important component in rehabilitation, stating that "patients should have access to specialist individual or group-based neuropsychological interventions to facilitate long-term psychological, family and social adjustment, including sexual relationships" (p. 45).

3.1.1.6 Professionals' perspective

There are only three studies addressing the perspectives of professionals on communicating about sexual issues post-TBI. Hough (1989) conducted a survey of 32 professionals working for a TBI rehabilitation program. 91% considered sexual adjustment to be as important as any other major aspect of rehabilitation, with 94% agreeing that sexual adjustment problems and difficulties with self-esteem might develop if no information on sexuality was

provided. However, the general stance was to avoid the topic if the service-user did not raise it. Similarly, Ducharme and Gill (1990) provide a summary of an unpublished survey of 129 professionals. The results indicated that although 79% agreed that sexual adjustment is as important for patients as any other area of rehabilitation, only 9% indicated that they felt comfortable discussing this with service-users and regularly include the topic in their rehabilitation plans. 51% of staff took a reactive approach, again only addressing sexual issues when the person with TBI raised the topic first. 41% said that they feel uncomfortable because they lack information or experience in this area.

Katz and Aloni (1999) conducted a survey of 30 professionals who work with people with TBI in the later stage of the rehabilitation process, using an open-ended questionnaire administered via an interview. The first part of the questionnaire focused on identifying the problems that prevent persons with TBI from having a fulfilling sex life, as perceived by professionals. The results indicated that professionals perceived sexual difficulties to be primarily a consequence of the emotional and behavioural impact of TBI, which in turn affects the dyadic relationship, and secondly from a lack of social opportunities. The professionals believed that sexual dysfunction is secondary to the injury and that controlling behavioural, social and dyadic problems would lead to a decrease in sexual complaints. The second part of the questionnaire focused on identifying effective therapeutic techniques. On the whole, it was found that professionals did believe there was a place for sexual rehabilitation during the early rehabilitation process, however, several barriers to addressing sexual issues were reported. This included personal embarrassment, lack of knowledge, no available training, no available supervision, and the lack of a systematic approach to the sexual rehabilitation of persons post-TBI.

Although there are a limited number of studies specifically investigating professionals' perspectives of sexuality after TBI specifically, other studies have investigated the views of professionals in more general neurorehabilitation settings. Staff in these settings are likely to work with people who have experienced a TBI, as well as other neurological conditions such as multiple sclerosis, spinal cord injury, and other forms of acquired brain injury (ABI) (e.g.

stroke). Haboubi and Lincoln's (2003) survey of 813 healthcare professionals in the UK (nurses, doctors, physiotherapists and occupational therapists) indicated that although 90% agreed that sexual issues ought to be addressed as part of the total holistic care of patients, 68% admitted that they had never initiated discussion about sexual issues with patients, 26% had initiated the discussion a few times, and only 6% initiated such discussions on a frequent basis. This mirrors the findings of Ducharme and Gill (1990) by indicating that there is a clear discrepancy between what professionals feel is important to address with patients, and their ability to meet their needs in practice.

A number of perceived or actual barriers have been reported which discourage professionals from having such discussions with service users in neurorehabilitation settings. This includes a lack of education or training (Baker & Shears, 2010; Haboubi & Lincoln, 2003), believing that it is not their responsibility or that it is outside their purview of care (Booth, Kendall, Fronek, Miller, & Geraghty, 2003; Herson et al., 1999), a lack of time (Haboubi & Lincoln, 2003; Herson et al., 1999; Tepper, 1997), inadequate support or no facility policy on sexuality (Davis & Schneider, 1990; Foley et al., 1999), the perception that sexuality-related issues are not appropriate for discussion with their service-users (Booth, Kendall, Fronek, Miller, & Geraghty, 2003; Herson et al., 1999; Tepper, 1997), personal embarrassment or discomfort (Baker & Shears, 2010; Haboubi & Lincoln, 2003), religious views, and homophobia (Baker & Shears, 2010). Furthermore, professionals' decisions whether to discuss sexual issues was affected by a number of service-user characteristics, including the patient's age (61%), physical wellbeing (54%), gender (52%), and their marital status i.e. whether they were in a stable relationship (42%) (Haboubi & Lincoln, 2003).

Haboubi and Lincoln's (2003) study suggests that these barriers may operate differently for professionals of different professional background. For example, doctors were found to be most involved in sexual issues, whereas therapists (occupational therapists and physiotherapists) were less likely to have received training and reported less comfort in discussing sexual issues.

The majority of research investigating professionals' perceptions and experiences of discussing sexuality after TBI has been based on quantitative survey data (Ducharme & Gill, 1990; Haboubi & Lincoln, 2003; Hough, 1989), which does not lend itself to in-depth and nuanced understanding of phenomena. An approach which strives to achieve a greater understanding would therefore be useful, and this would also answer Haboubi and Lincoln's (2003) call for more qualitative research into the area.

Indeed, only one qualitative study investigates professionals' views of discussing sexuality with service users with TBI (Katz & Aloni, 1999). The findings of this study concur with the results from quantitative studies, whilst providing the additional benefit of richness of data not possible in quantitative studies. However, this study is limited for a number of reasons. Firstly, the authors provide little detail about the underlying theoretical framework or method of qualitative analysis. Of the information available, it appeared that a relatively simple method of summarising responses was used. Secondly, the authors did not use direct quotations from participants meaning that it was difficult to distinguish between the original data and the researchers' analytical interpretation. Generalisability of this study is also limited given that this study was conducted with a small sample of 30 participants from the same area of Israel. With this study being conducted thirteen years ago, a more recent investigation is necessary. Finally, another methodological limitation relates to the sampling method; the majority of populations are self-selected, and therefore there might be important differences between those who chose to take part in the research and those who did not. This may be confounded by questions that ask therapists to report on aspects of their own practice which could be viewed as negative. This may be a difficult limitation to overcome, but perhaps being aware of this is useful when applying the research to broader populations.

3.1.1.7 Management of sexuality in other healthcare settings

The broader literature also provides useful material for understanding professionals' perspectives and experiences of communicating about sexuality.

Overall, research suggests that it is not just in TBI and neurorehabilitation settings that issues of sexuality are seldom addressed. For example, research has indicated that professionals tend to ignore or avoid sexual issues in primary care settings (Gott, Galena, Hinchliff, & Elford, 2004; Hinchliff, Gott, & Galena, 2004; Humphery & Nazareth, 2001; Temple-Smith, Mulvey, & Keogh, 1999), stroke services (McLaughlin & Cregan, 2005; Tepper, 1997), cancer services (Cox, Jenkins, Catt, Langridge, & Fallowfield, 2006; Hordern & Street, 2007; Stead, Brown, Fallowfield, & Selby, 2003; Zeng, Liu, & Loke, 2011), intellectual disabilities services (e.g. Abbott & Howarth, 2007), mental health services (McCann, 2010a; Nnaji & Friedman, 2008; Quinn, Happell, & Browne, 2011; Rele & Wylie, 2007), coronary care settings (Ivarsson & Fridlund, 2009; Ivarsson, Fridlund, & Sjöberg, 2010), renal and cardiology services (Ho & Fernández, 2006), and in general nursing on medical and surgical wards (Saunamäki, Andersson, & Engström, 2010). Similar barriers and facilitators have been identified to those listed above.

Dyer and das Nair (2012) conducted a review of eight qualitative studies conducted in the UK in order to provide insight into professionals' perceptions of communicating about sexuality with service-users. Studies were based in primary care settings, cancer services, intellectual disabilities services and a Disability and Rehabilitation Team. The authors concluded that organisational, structural and personal factors have a combined effect on professionals' decision whether to initiate discussions of sexuality with service users (see figure 4)

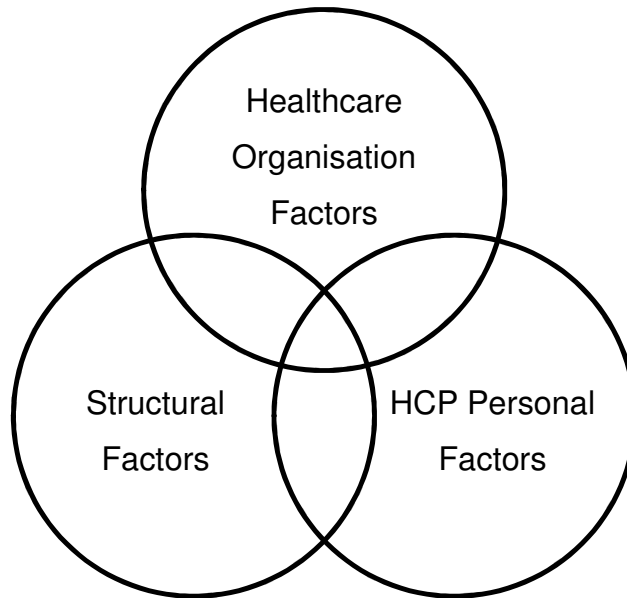


Figure 4. Factors influencing professionals' discussion of sexuality with service-users (Dyer & das Nair, 2012).

Organisational factors include a lack of time, resources, policy, and training, which can prevent professionals from opening up discussions about sexuality. In addition, the organisation's shared values, norms, and practices are likely to guide their behaviour. Structural factors represent the social, economic, and political aspects of wider society over which professionals have little personal control. The organisational barriers listed above are likely to be influenced by the wider economic climate, current government incentives, and restrictions. In addition, views of sexuality are likely to be influenced by wider societal discourses, including the categorisation of older people and people with intellectual disabilities as "asexual", and the view that heterosexuality is the "norm". Personal factors relate to the knowledge, motivation, and attitudes of individual professionals, which could work to impede or facilitate discussions. Finally, professionals' interpretations of the concept of sexuality could act as a "filter" to determine whether, and which issues are raised.

Dyer and das Nair (2012) also reported that these barriers are exacerbated within certain service-user populations; those of the opposite gender, black and

minority ethnic groups, older service-users, non-heterosexual service-users, and those with intellectual disabilities. It would be useful to investigate whether these same barriers are highlighted by professionals working with TBI populations.

3.1.2 RATIONALE FOR CURRENT STUDY

A review of the literature indicates that TBI can lead to a number of barriers to the successful development, expression, and maintenance of sexuality, including intimacy and relationships. Despite this, research indicates that sexual issues have been ignored in TBI rehabilitation. A literature search identified little existing data on professionals' subjective understanding of, or attitudes and beliefs, about the issue.

Quantitative survey studies have established a useful starting point, however, a greater in-depth understanding of the perceptions and experiences of having discussions is warranted. The one qualitative study that has been conducted within a TBI setting has a number of limitations (as highlighted previously). Qualitative studies (including the recent systematic review of qualitative studies by Dyer and das Nair, 2012) in other healthcare settings have also offered valuable insight, but a deeper understanding of how these barriers operate specifically for a TBI population is required.

Research into the views and experiences of professionals in communicating about sexuality post-TBI will expand the theoretical and clinical knowledge of how to manage sexual issues in the TBI population. This will have implications for future clinical practice, as it will enable links to be drawn from the findings to actions that can be taken clinically. By promoting a greater psychological understanding of the barriers which operate within TBI services, as well as how professionals feel they could be overcome, the sexuality of people who have experienced a TBI may be better able to be addressed. Improving communication about sexuality could result in earlier identification of sexual difficulties, earlier interventions and ultimately prevent future deterioration in the

sexual function, emotional well-being and overall quality of life in people with TBI.

Finally, it is hoped that this research should provide a basis upon which more qualitative and quantitative research could be developed, such as by implementing and evaluating the effectiveness of interventions to support people experiencing changes in sexuality following a TBI.

3.1.3 RESEARCH AIM

The overall aim of this study was to address the shortcomings of the existing research base by providing a more comprehensive understanding of the perceptions and experiences of professionals of having discussions about sexuality with service users following TBI.

3.2 EXTENDED METHODOLOGY

This section expands on the journal article by providing a rationale for the methodology chosen, with limitations outlined. The research procedure is then described. A rationale for the use of Thematic Analysis (TA) is provided with a consideration of its limitations. This section closes with a discussion of the epistemological underpinnings of the current study, and the researcher's statement of perspective.

3.2.1 RESEARCH DESIGN

3.2.1.1 Rationale for qualitative methodology

There are many differences between the quantitative and qualitative modes of enquiry. During the Positivist era, quantitative research focused on uncovering a single objective reality by measuring observable human behaviour and through the use of statistical analysis. At the other end of the research spectrum, (qualitative) constructivist paradigms are based on the idea that multiple realities exist based on social constructions (Guba & Lincoln, 2005).

Qualitative methodology is considered to be more suited to research which has the aim of exploring the personal experiences of participants, and the way in which meaning arises from these experiences (Willig, 2008). It is also considered most appropriate when there is little existing knowledge into a subject area (Barker, Pistrang & Elliot, 2002), hence the decision to adopt qualitative methodology for this study.

3.2.1.2 Rationale for focus groups

Focus groups have been defined by Morgan (1996) as "a research technique that collects data through group interaction on a topic determined by the researcher" (p. 130). The group is 'focused' in the sense that it involves some kind of collective discussion (Kitzinger, 1995).

Focus groups have become a regularly used research method within the field of health and social care (Robinson, 1999; Webb & Kevern, 2001; Wilkinson, 1998). They have been used to investigate professionals' knowledge, attitudes, perceptions and beliefs about a variety of clinical problems (e.g. Hazelton, Rossiter & Milner, 2006) and to understand how professionals define their roles in relation to certain clinical problems (e.g. Miller & Jaye, 2007). Focus groups were selected as the means of data collection this study for a number of reasons:

1. By examining group dynamics, focus groups allow examination of not only *what* participants' attitudes and beliefs are, but also *why* they hold them and under what circumstances they might vary (Kitzinger, 1995), and this was considered to be in line with the researchers' critical realist stance that there are different angles on a true reality;
2. The type and range of data generated through the interaction of the group are often deeper and richer than that obtained from one-to-one interviews (Morrison-Beedy, Côté-Arsenault, & Feinstein, 2001; Thomas, MacMillan, McColl, Hale, & Bond, 1995);
3. Given that what participants say can be confirmed, reinforced or contradicted within the discussion (Webb & Kevern, 2001), the method has natural quality control and is considered to have a high level of face validity (Kreuger, 1994);
4. It was felt that some professionals may be relatively unfamiliar with sexual issues after TBI, may feel that they had little to contribute, and may therefore be reluctant to partake in a one-to-one interview (Morgan, 1988). Focus groups therefore provide a 'safe' forum for participation e.g. participants do not feel obliged to respond to every question (Basch, 1987). Furthermore, through a sense of group membership and cohesiveness, focus groups can support and empower participants to make contributions (Goldman, 1962; Peters, 1993; Kitzinger, 1995);
5. In focus groups, participants talk primarily to each-other rather than to the researcher, and are therefore are more likely to do so in a way

which is closer to their naturalistic, everyday conversation. As a consequence focus groups are more sensitive than one-to-one interviews to the participants own language, concepts and cultural values (Tiggemann, Gardiner & Slater 2000);

6. Because of the interaction among group participants, the amount of interaction between the researcher and participants is often reduced. This reduces the level of 'control' which the researcher has over the direction of the focus groups, giving a more prominent role to the participants' opinions than in one-to-one interviews, and allowing the opportunity for unanticipated issues to emerge (Madriz, 2000; Morgan, 1996).

3.2.1.3 Limitations of focus groups

Using the focus group method also has limitations which must be considered:

1. The freedom of participants to raise issues of importance to them could potentially be problematic if participants are drawn to topics that are not perceived by the researcher to be relevant to the research question;
2. The contributions that people make are likely to be at least influenced, if not constrained by the group situation. For example, dissenting views held by the less confident participants in the group may be 'censored' (Sim, 1998), or the presence of dominant personalities within the group may control, undermine, or stifle the responses of other group members (Carey, 1994; Fontana & Frey, 1994). This may lead to the suppression of a wider range of views and attitudes, creating a false impression of conformity amongst the professionals. Although this issue of group dominance may not be able to be fully resolved in the context of this study, the researcher felt it important to consider this issue when conducting the focus groups and analysing the data;

3. Some participants may be unwilling to speak their mind for fear of retribution (Kitzinger, 1995), for example, professionals may be afraid of discussing organisational problems within their team in-case this is reported back to their manager. It is hoped that this problem will be overcome at the outset of the focus groups when the group rule concerning confidentiality is outlined;
4. There is the potential for 'social loafing', where some participants will sit back and not participate (at least verbally) (Asbury, 2005). This may particularly be the case if the group size is too large (Parsons & Greenwood, 2000).

3.2.2 PROCEDURE

3.2.2.1 Focus group composition

Professionals were targeted for this study given that they constitute the 'first line' of healthcare provision in the post-TBI period. This involves frequent and regular contact with individuals who have experienced a TBI, as well as their families. The role of professionals in TBI rehabilitation priorities return to functional activities, thus the management of sexual wellbeing appears to be part of their role.

Pre-existing groups: The focus groups comprised of groups of pre-existing groups of professionals, that is, those that already work together. This approach was chosen for the following reasons:

1. It was felt that participants may be comfortable sharing their thoughts and ideas with other individuals who they know, thus facilitating spontaneity and openness (Kitzinger, 1995);
2. It was felt that colleagues would be able to relate each other's comments to experiences in their shared daily lives. This may mean that they are able to agree with, contradict and challenge each-other, for example, on what they claim to believe and how they actually behave (Kitzinger, 1995);

3. It was felt that it would encourage participation of professionals from different disciplines, thus maximising the exploration of different perspectives. The use of specially formed groups may have resulted in an oversubscription of certain professional background;
4. Pre-existing groups enable researchers to tap into fragments of 'naturally occurring' data, such as that collected through observational methods (Kitzinger, 1994). It was felt that this would enable the researcher to investigate how professionals talk about sexuality within the groups in which they regularly operate, and to explore the context in which ideas are formed and decisions are made.

However, whilst focus groups may approximate to observational methods, it is acknowledged that the focus groups were artificially set up for the purpose of this study. Rather than automatically assuming that the group reflects 'everyday interactions', the group was used to encourage professionals to engage with each other and to "draw out the cognitive structures which have previously been unarticulated" (Kitzinger, 1994, p. 106).

Group size: Focus group texts have typically advised that groups consist of between six and eight participants as the optimum size for discussion (Kreuger & Cacey, 2000; Bloor, Frankland, Thomas & Robson, 2001), but groups as small as three (Bloor et al, 2001; Barbour & Kitzinger, 1999) and as large as fifteen (Morgan,1992) have been suggested. Focus groups in this study contained between four and eight participants, which was largely determined by the willingness and availability of staff to participate in the project. It was felt that this number of participants was small enough to allow each participant enough time to express their views and experiences, yet large enough to allow a wide range of diverse responses to be shared.

Inclusion/exclusion criteria: Professionals were able to participate in the study if they currently worked with service-users that have experienced a TBI; if they were willing to respond to open-ended questions pertaining to their personal experiences of discussing sexuality with service users in a focus group

setting; and if they consented to take part in the study. These criteria were assessed initially by the participant themselves but later confirmed by the researcher during consent.

3.2.2.2 Number of groups

Focus groups texts have indicated that projects should consist of three to five groups (Morgan, 1997). The justification for this is that the data becomes “saturated”, and more groups seldom provide new insights (Morgan, 1997; Zeller, 1993). The variation between three and five will depend on a number of factors, including group composition and level of structure - The more diverse the group and the more open-ended the questions, the greater the number of groups required (Morgan, 1997). In this study, four focus groups were conducted. This was considered sufficient given the homogenous nature of the sample, the focused questions, and because of the in-depth method of data analysis used.

3.2.2.3 Sampling and recruitment

Sampling procedures in qualitative research are not so rigidly prescribed as in quantitative research (Coyne, 1997). As is typical in focus group research, this study used selective (purposeful) sampling (Macleod Clark, Maben & Jones, 1996). This involves selecting people who could explore the research aim and meet the requirements of the study (Boeje, 2010).

Groups of professionals that work with people that have experienced a TBI were recruited either from the National Health Service (NHS) (local TBI or neurorehabilitation teams) or from a national charity which supports people affected by TBI. Initially one professional from each team (the manager or a senior member of staff) was contacted via email or telephone. This professional (the ‘lead professional’) was informed of the purpose of the study, the amount of time that would be required of the professionals, and what would happen during the focus group. If interest and willingness for the team to be involved in the

study was shown, the lead professional was then asked to distribute the Participant information sheet within their usual place of work. Professionals were able to contact the researcher individually for further information about the study. Finally, the lead professional was then asked to contact the researcher directly to confirm the number and names of participants that would be willing to take part, and were also responsible for arranging an appropriate time and place to conduct the focus group.

3.2.2.4 The focus group sessions

The focus groups took place between April and September 2012, and were facilitated by the primary researcher. The groups began by reviewing the purpose of the study, Participant information sheet, Consent form and procedure. Group ground rules were then established, including the importance of maintaining confidentiality by not revealing personally identifiable information about other participants. Participants were given the chance to ask questions prior to written consent being sought. Participants were informed that they would receive a summary of the research, once written up: For this reason, participants were asked to provide contact details which would be held on record.

Given that certain demographics have been identified as impacting on communication about sexuality, it was considered important to collect this information from participants. Demographic and clinical information was therefore collected on the day of the focus group, and consisted of: Age range, profession, years of experience working with service users, and years of experience working with service users who have experienced a TBI.

Each group was audio-recorded for later transcription using a digital dictation device. In addition, field notes were maintained based on the guidelines outlined by Cote-Arsenault and Morrison-Beedy (1999), including memos on the seating arrangement, non-verbal behaviours, group interactions, initial impressions and

reflections, and striking themes. These field notes were used as an additional reference during data analysis.

3.2.2.5 Semi-structured interview schedule

A semi-structured interview guide was developed to guide and open up dialogue about communicating with service users about sexual issues post-TBI. As with all semi-structured interviews, the questions were used as a guide only. Beyond this, an open and flexible approach was used: Questions were supplemented by clarifying, challenging and probing questions where appropriate, with the aim of yielding more accurate and in-depth responses (Krueger, 1994). However, since the focus is on the professionals' everyday ways of talking, the researcher opted for a 'low' moderator style, that is, a modest role for the moderator in discussion (Morgan, 1997). This ensured that the group directed the discussion as opposed to the researcher (Wilkinson, 1998), and also ensured that the research remained grounded in the participants' lived experiences.

3.2.2.6 Ethical considerations and approval

The project followed the British Psychological Society Ethical Guidelines (Francis, 2009). Ethical approval was gained from the University of Lincoln's Ethics Committee on 2nd November 2011 (with an amendment being approved via email on 8th January 2012). Subsequently, Research and Development (R&D) approval was sought from two NHS trusts. All suggested amendments were adhered to. Final approval was gained from the first NHS trust on 29th March 2012 (with an amendment being approved on 24th April 2012), and from the second NHS trust on 28th May 2012.

There were a number of ethical considerations associated with this study. Firstly, in order to ensure that participants were fully informed, a Participant information sheet was provided to all participants. Secondly, the researcher and each participant signed and dated the consent form before the focus groups

commenced. Thirdly, participants were informed that they could withdraw their data for up to two weeks following the focus group. Forth, and in accordance with the Data Protection Act, all data was kept secure and transported to a locked filing cabinet at the University. Fifth, the confidentiality of participants has been ensured by using participant identification numbers were used in replacement of names, and omitting all other identifiable information. Finally, in accordance with the British Psychological Society's (BPS) recommendations (Francis, 2009), participants were informed that they would receive a summary of the research findings.

3.2.3 DATA ANALYSIS

3.2.3.1 Different methods and rationale for TA

Even within the qualitative framework there are numerous approaches to data collection, representing a diverse range of epistemological perspectives and theoretical frameworks. TA defined as “a method for identifying, analysing and reporting patterns (themes) within data” (Braun & Clarke, 2006, p.79), prevailed as the most appropriate means of analysis for this study. TA has been described as a foundation method which all qualitative skills and methods can be built. TA has a clear methodological structure, which provides a framework that ensures that the captured data is analysed in a systematic, transparent, and rigorous way.

TA was also chosen because of the aims of the current study, the existing literature, and the researcher's epistemological stance. A comprehensive critique of the different modes of enquiry is beyond the scope of this paper. However, the section below outlines the three main alternative methods of analysis, whilst further developing an argument for the use of TA.

Interpretative Phenomenological Analysis (IPA) explores individuals' beliefs about a phenomenon and the meaning to them as an individual, whilst also endeavouring to understand the essence of that account (Smith, Flowers &

Larkin, 2009). Whilst TA shares some similarities with IPA in that they both focus on subjective human experience, it was felt that TA offers a broader analysis as it can incorporate social and cultural phenomena as well. It was also felt that IPA would not lend itself as easily as TA to the analysis of focus group data, or that it would represent too much of a fundamental shift from the ideographic to be considered “true” IPA. It was also felt that IPA interprets “too far” beyond what is required for this study. Finally, both IPA and TA recognise the influential role of the researcher. However, in TA this plays less of a central role and it was therefore considered to be slightly better suited to the researcher’s epistemological stance.

Grounded Theory (GT) aims to systemically facilitate the process of theory generation through the application of saturating data (Willig, 2008). The TA approach taken shares the systematic yet flexible and inductive qualities of GT, and can also be used to build and develop theory. However, TA is not restricted to this purpose and was therefore considered to have a wider breadth of scope.

There are a number of strands of Discourse Analysis (DA), but all attain an interest in the role of language and the construction of social realities (Willig, 2008). Language and discourse are seen as the means by which a researcher can access an individual’s version of the world. The aim of this study was to understand the perceptions and experiences of professionals, rather than focussing exclusively on linguistic properties, and DA was therefore not considered the most appropriate means of analysis.

3.2.3.2 Transcription

All four focus groups were transcribed by the researcher. Transcription was guided by a number of *a priori* decisions, which were made based on the aims and methods of the research, as well as being influenced by the researcher’s own epistemological and theoretical views, but essentially a modified Jeffersonian transcription style was employed (Jefferson, 1984). Transcripts were transcribed verbatim (an ‘orthographic’ account) and included verbal utterances (such as “ah”, and “hmm”), pauses, emotional comments (e.g.

laughter), and punctuation, as it was felt that this could alter the meaning of the data.

3.2.3.3 A number of *a priori* decisions

A TA was carried out within a contextualist, critical realist framing, following Braun and Clarke's (2006) guide. Prior to commencing analysis, a number of *a priori* decisions were made:

Firstly, themes may be generated inductively from the raw information, or generated deductively from theory and prior research (Boyatzis, 1998). An inductive, bottom-up approach was used to ensure that the analysis was firmly grounded in the data, and to limit applying pre-conceived codes (Frith & Gleeson, 2004). The analysis therefore has some overlap with GT. This enables the stories and experiences of the participants to be voiced as accurately and comprehensively as possible, and also allowed for previously unforeseen themes to emerge and shape the direction of the study. However, it is acknowledged that such analyses can never be free from the researcher's theoretical and epistemological commitments, and that the researcher has an active role in identifying themes, selecting which are of interest and reporting them to readers (Taylor & Ussher, 2001).

Secondly, it was important to consider what counts as a theme. This study is based on the principle that the 'keyness' of a theme is not necessarily dependent on quantifiable measures, and thus themes do not necessarily represent the most prevalent aspects of the dataset (Braun & Clarke, 2006; Buetow, 2010). Instead, the key role of a theme was to capture something of importance in relation to the research question.

Thirdly, a decision revolved around whether to identify themes at the semantic (manifest) or latent level. At the semantic level, themes are identified within the explicit or surface meanings of the data, and thus are directly observable in the information (Boyatzis, 1998). A TA at the latent level aims "to identify or examine the underlying ideas, assumptions, and conceptualisations—and

ideologies—that are theorised as shaping or informing the semantic content of the data” (Braun & Clarke, 2006, p. 84). The method of analysis therefore overlaps with methods used within a constructionist paradigm, such as DA and Thematic-DA (e.g. Singer & Hunter, 1999; Taylor & Ussher, 2001). Both approaches deal with interpretation, but the interpretations vary in depth and level of abstraction. The semantic level of analysis was chosen to ensure that the analysis remains firmly grounded in the data.

3.2.3.4 The TA Procedure

The analysis followed Braun and Clarke (2006)’s comprehensive six phase guide of TA (see Table 4). The authors describe how the analysis process begins when the data is transcribed, followed by repeatedly reading the data in an ‘active’ way. As mentioned earlier, the researcher transcribed all four recordings, and also spent time checking and becoming familiar with the data. This process of immersion also allowed initial ideas, patterns and meanings to be created.

The second stage involved systemically going through the transcripts line-by-line, giving full and equal attention to each data item. This involved making annotations (initial codes) in the margin, representing features of the data identified as being important in answering the research question, and as interesting to the reader. Codes consisted of descriptive labels of each sentence, as well as other interesting words, phrases or concepts. This process is considered part of the analysis process given that the researcher is looking for connections between the codes generated and collating the coded data into provisional groups (Miles & Huberman, 1994). At this stage, the researcher’s supervisor was consulted and transcripts were reviewed independently (see 2.2.4 Establishing quality).

The third stage begins by collating the initial codes that have been identified across the data set, and sorting them into potential themes. According to Braun and Clarke (2006), “A theme captures something important about the data in

relation to the research question, and represents some level of patterned response or meaning within the data set” (p. 82). This was done via creating a comprehensive list of all the codes, separating them on separate pieces of paper, and organising them into theme piles. Particular attention was paid to similarities and differences between the professionals’ accounts. A ‘miscellaneous’ theme was also used temporarily for codes that did not seem to fit into the other main themes. This process enabled links to be made between codes, themes and between different levels of themes (main themes and subthemes).

In the fourth stage, transcripts were revisited to check whether the initial stage of clustering was an accurate representation of the data extracts and of the data set as a whole. Once the themes had been reviewed, a thematic map (i.e. an overall conceptualisation of the data patterns and relationships between them; Braun and Clarke, 2006) was then developed. During this process, some candidate themes were broken down into separate themes where the data was too diverse. Where there was considerable overlap, some candidate themes were collapsed into an overall theme. Some themes were discarded completely where there was not enough data to support them. This process resulted in several versions of the thematic map being developed.

Fifth, the themes were refined, defined and given a clear name to capture the ‘essence’ of what the theme is about. Finally in the sixth stage, the themes and data extracts were selected and reported in the write-up in order to address the research aims.

Table 4. Six stage process of thematic analysis (adapted from Braun and Clarke, 2006)

| Stage | Description |
|----------------------------|---|
| Data familiarisation | Data transcription, repeated reading, and noting down initial ideas. |
| Generating initial codes | Systematically coding features of interest, and organising into meaningful groups. |
| Searching for themes | Collating codes into potential themes, and gathering data relevant to each theme. |
| Reviewing themes | Checking themes work in relation to the data extracts and entire data set, and generating a thematic map. |
| Defining and naming themes | Refining the themes, generating clear definitions and names for themes. |
| Producing report | Selecting themes and data extracts to report that reflect the research aim. |

It is important to note that this procedure was applied flexibly and there was a recursive process of movement back and forth throughout the stages as necessary, comparing 'incidents' across the entire dataset. As the themes were refined, the transcripts were read repeatedly to look for further examples as well as for disconfirming data.

3.2.3.5 Group interaction data

Focus group interaction data reflects the interactive patterns within focus groups (Duggleby, 2005). This includes everyday social processes of communication, such as joking, teasing, boasting, arguing, challenge, and disagreement (Wilkinson, 1998). It also includes the consideration of whether the participants' contribution is in accord or in contrast to the majority opinion, as well as how a

participant's contribution may have been affected by previous comments in the session. Censoring, conformity and groupthink are also potential considerations (Carey & Smith, 1994).

The interactive feature of focus groups has been stressed as pivotal to the method (Kitzinger, 1994), yet there have been few attempts to derive analytical principles of examining group interaction data (Lehoux, Poland, & Daudelin, 2006). Duggleby (2005) presented three potential methods for analysing group interaction data:

1. Providing a descriptive analysis of the group dynamics, such as by considering the 12 questions set out by Stevens (1996). Whilst providing structure, this approach does not permit consistency as the group interaction data is not analysed using the same methodological approach. Secondly, there is a risk of ignoring and not integrating the interaction data with other types of focus group data (Duggleby, 2005);
2. Incorporating the data into transcripts, such as providing interpretations about nonverbal behaviour and group interaction in parenthesis (e.g. Morrison-Beedy et al., 2001). A disadvantage of this approach is that the actual group interaction data that supported the researchers' interpretations are not typically reported, making an accurate audit trail difficult (Duggleby, 2005);
3. Analysing the group interaction data separately using the congruent qualitative methodological approach, and then integrating it with the rest of the data.

For the current study, the latter approach was used. This involved analysing the group interaction data found in transcripts and field notes in line with the TA approach used. This initially involved coding group interaction data in the right hand margin of the transcripts (such as 'query', 'agreement' 'challenge', 'defending opinion', 'change of mind', and 'sharing personal experience'). Codes were guided by the analytical template and interactive processes

explicated by Lehoux et al., (2006). The findings were then reported as part of the description of other themes (Duggleby, 2005).

3.2.3.6 Critique of TA

Although Braun and Clarke (2006) offer practical and accessible guidelines for conducting TA, they have argued that researchers should be adaptable within this framework. Whilst the flexibility of TA could be viewed as an advantage, this provides little guidance for the researcher when deciding what aspects to focus on (Braun & Clarke, 2006). The flexibility also means that TA has not developed an 'identity' as an analytical method, unlike more 'branded' forms of analysis like IPA or DA. There is also the danger of TA having limited interpretative power beyond description, if not used within an existing theoretical framework that anchors analytical claims that are made (Braun & Clarke, 2006).

Other criticisms of TA relate to criticisms of qualitative methods as a whole, for example the perception that 'anything goes' (Braun & Clarke, 2006). Bryman (2001) has argued that the context of data is lost through the process of coding. Other disadvantages appear when TA is compared to other qualitative methods. For instance, in contrast to DA, (semantic) TA does not allow the researcher to make claims about language use, or the fine grained functionality of talk. Despite this, it is felt that a rigorous thematic approach can offer insightful analysis, unanticipated insights, and can be useful in answering particular research questions.

3.2.4 ESTABLISHING QUALITY

There is some debate about the use of validity and reliability measures in qualitative research, with concerns about limiting freedom and stifling methodological development being raised (Elliott, Fischer, & Rennie, 1999; Parker, 2004; Reicher, 2000). Despite this, there is a general consensus that qualitative inquirers need to demonstrate that their studies are credible and trustworthy, especially given that common criticism is that qualitative results are

anecdotal. This is important when working in a field such as clinical psychology, which places high emphasis on evidence-based practice.

Although a common standard of excellence for conducting good qualitative research might not be attainable (Reicher, 2000), procedures and guidelines have been developed for enhancing credibility. Among the most commonly used procedures are audit trails, thick and rich description, triangulation, member checking, and researcher reflexivity (Creswell & Miller, 2000; Lincoln & Guba, 1985). A description of these procedures is provided below:

Audit Trails: Keeping an audit trail refers to maintaining careful documentation of all components of the study (Carlson, 2010). This was achieved by the researcher following Braun and Clarke's (2006) six stage TA procedure, which was recorded in a research diary. This diary was maintained throughout the entire research process, from formation of the research aim to the write-up, and was used to record correspondence, focus group field notes, initial ideas and interpretations, code and theme development, and various drafts of analysis. Furthermore, the results and discussion sections contain extensive direct quotations from the participants' own accounts, as well as from the researcher's field notes based on focus group observations. This provides readers with the opportunity to assess the validity of the themes highlighted.

Thick and rich description Thick description involves describing the setting, participants, and themes in rich detail (Creswell & Miller, 2000). As qualitative researchers are more concerned with corroborating findings over time across similar situations than inter-study replication (Carlson, 2010), one function of thick description is to enable readers to make decisions about the applicability of the findings to other contexts (Creswell & Miller, 2000). Thick description also draws the reader closer into the events being described and can increase a sense of connection with the participants (Creswell & Miller, 2000). The current study provides details of settings, participants, data collection and analysis procedures as far as possible, whilst maintaining confidentiality. Furthermore, group interaction data is presented in order to bring extracts 'to life'.

Triangulation: Triangulation refers to the action of combining research perspectives and methods in order to gain a fuller perspective of the situation that is being investigated (Flick, 2002). Denzin (1978) proposed four methods of triangulation:

1. Data triangulation (using a variety of sources in a study, including time, space and person);
2. Investigator triangulation (using several different researchers or analysts);
3. Theory triangulation (using multiple perspectives to interpret a single set of data);
4. Method triangulation (using multiple methods to study a single phenomenon).

The research aim should be used to consider if triangulation is necessary. Sim and Sharp (1998) have suggested that where research questions have specific focus, a single-method research may be the most appropriate, hence the decision to adopt a single-method approach in this study. However, this study did employ data, investigator and theory triangulation. Investigator triangulation involved the researcher and her research supervisor independently coding transcripts and themes. This was done to cross-check credibility of coding and the themes derived, and also to ensure that the researcher's perspective on the data could be understood and followed by others (Boyatzis, 1998; Yardley, 2008). Through meetings to discuss the data, the researcher was able to consider other possible competing interpretations and explanations (Barbour, 2001). This enabled codes and themes to be revised prior to the final group of main themes and subthemes being developed.

Participant validation: Also known as member checking, this process involves cross checking research findings with participants (Barbour, 2001). Despite acknowledging the advantage of participant validation in terms of verifying the accuracy of the data, these techniques were not used due to a number of practical and ethical reasons: Firstly, member checks rely on the assumption that there is a fixed truth of reality that can be accounted for by a researcher

and confirmed by a respondent, a position that not fit with the critical realist epistemology adopted by the researcher; secondly, it was felt that it may be difficult to apply to focus groups where different members may have different views of the same data; thirdly, the participant's interpretation may change between the time of data collection and the time of theme check, for example, new experiences of communicating about sexuality may inform new interpretations of the data; fourth, in the time pressured context of healthcare services, it is important to consider that exercises such as reading drafts make considerable demands on participants' time.

Researcher reflexivity: In quantitative research, there are ways to drastically reduce the influence of the personal biases that researchers bring to the data. However, in qualitative research, researcher bias is not necessarily viewed as problematic, as long as researchers bring their preconceived beliefs into the dialogue (Harry, Sturges & Klingner, 2005). Reflexivity involves the recognition by researchers that their biases, assumptions, and aspects of their backgrounds will have "a significant influence on the development of the research and the engagement of the participants" (Curtin & Fossey, 2007, p. 92-93) and therefore researchers have a duty to be transparent about that influence in their reporting of data (Carlson, 2010). This is in line with the researcher's critical realist stance that the researcher is implicated in the analysis.

This study endeavoured to meet this criterion by stating the position of the researcher (See 2.2.6 Researcher's statement of perspective). In addition, the researcher used a research diary to record thoughts, impressions, feelings, and decisions, as well as reflections on how the researchers' own values, beliefs, assumptions and experiences will have influenced the interpretation and presentation of data. The researcher decided not to use a stage model of reflection as it was felt that this may restrict thought processes, instead preferring thoughts to flow freely.

Finally, the researcher also considered it important for rigour to be achieved by developing a systematic method congruent with the analysis method used. Indeed, Madill, Jordan, and Shirley (2000) have argued that the criteria for

evaluating qualitative research needs to be the specific epistemological and ontological framework of the methodology. This study therefore also applied Braun and Clarke's (2006) concise checklist of criteria for good thematic analysis.

3.2.5 EPISTEMOLOGICAL POSITION

TA has been criticised for not having a specific associated epistemological position, however, provided that the researcher clearly states their epistemological position from the outset, the method can be applied flexibly to answer a wide range of research questions (Braun & Clarke, 2006).

The epistemological position is formed through ideas about the type of knowledge sought, the nature of the world, and the researcher's role within the research (Willig, 2008). This study will be conducted within a critical realist framework, which sits between the two poles of essentialism and constructionism (Borrell, 2008). Within this paradigm, the data is seen to reflect some, but not all aspects of reality beyond the bounds of the research process. Critical realists desire an understanding of a single reality (Willig, 2008), whilst recognising that this reality has many facets that are interpreted by individuals in different and unique ways (Martin, 2010). The researcher acknowledges that participants' accounts and meaning-making will be influenced by their own background, personality, views, feelings, opinions, expectations, and the broader sociocultural context in which they give their account (Borrell, 2008)

Within the Positivist paradigm, the researcher is seen as objective and detached from their research. In contrast, the critical realist researcher acknowledges their responsibility in choosing and understanding the participant's version of reality, creating the findings in a joint collaborative process (Martin, 2010). The researcher recognises that themes do not simply emerge, but are actively sought out. Furthermore, the researcher will also bring her own preconceptions, personal, theoretical and political beliefs to the process of data collection and analysis (Taylor & Ussher, 2001).

3.2.6 RESEARCHER'S STATEMENT OF PERSPECTIVE

A researcher's statement of perspective is considered useful to help the reader interpret and understand the analysis (Elliott et al., 1999). To orientate you to the researcher, I am a trainee clinical psychologist, with experience working with service-users who have experienced a TBI in neurorehabilitation settings. Anecdotally and based on my own clinical observations, I was struck by how little the issue of sexuality was discussed, particularly given that many TBI survivors are in the midst of adolescence or young adulthood where establishing one's own sexuality is an important transition. I have come to the research with the assumption that sexual issues should be discussed more, and hold my own assumptions about what might hinder or facilitate such communication. I am aware that my training as a clinical psychologist will influence how I conceptualise TBI and sexual issues, as well as how I feel these issues should be managed. I.e. my knowledge of the pharmacological and medical management of sexual difficulties is minimal in comparison to my knowledge of psychological treatments.

3.3 EXTENDED RESULTS

This section elaborates on the main themes and subthemes described in the journal article. The thematic map (figure 5) illustrates the interactions between the six main themes, subthemes, and the research aim.

Data extracts from the focus groups are presented throughout to support each theme. As main themes and subthemes are not wholly independent, there will be instances where one quotation may be used to illustrate several themes. The choice as to which extract to use for which theme was made in relation to its perceived saliency, and to the extent to which they were perceived to offer knowledge relating to the theme.

3.3.1 FURTHER INFORMATION ON THEMES

3.3.1.1 Sexuality after TBI is a specialist issue¹⁴

Participants across all four focus groups perceived that they have a '**Lack of knowledge, skills and expertise**' to deal with the complexities of sexual issues after TBI, and this in turn prevents them from asking service-users about such issues. Some participants verbalised a direct link between a lack of knowledge, skills and training, and willingness to raise sexuality issues. Other participants highlighted a more indirect link, with '**Comfort and confidence**' as an intervening variable:

P6:1 I don't think we get any training on it, so I don't know how comfortable people would be. I don't think I would be very

P6:2 There is training under {organisation name}, there's a sex and sexuality course. I've not personally been on it so I don't really feel (.) comfortable

¹⁴ Throughout the Extended results section, main themes are identified in **bold**. Subthemes are identified by being in '**Quotation marks, bold and italicised**'. Subthemes mentioned but discussed elsewhere in the text are identified by being in '*Quotation marks and Italicised*'.

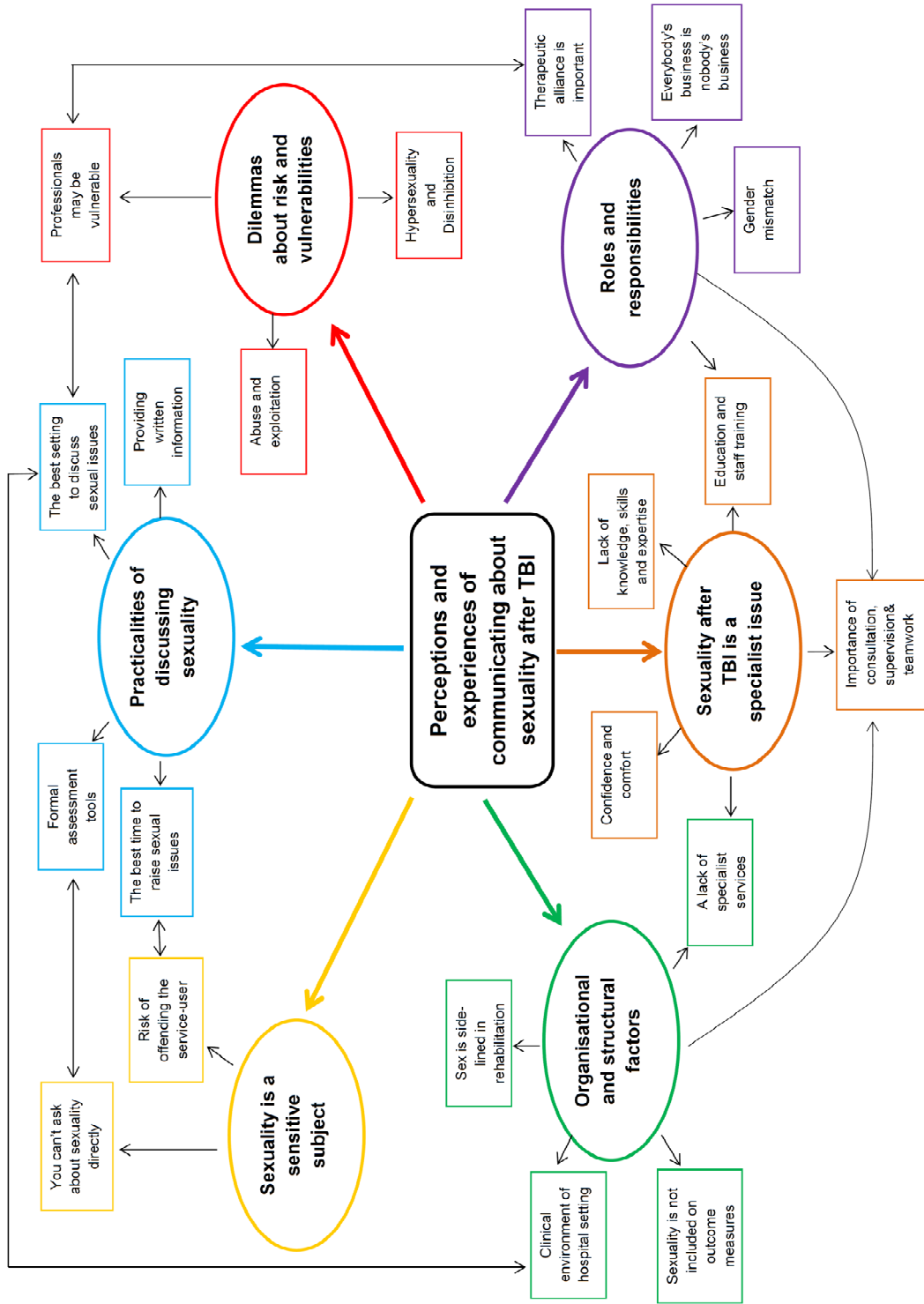


Figure 5. Final thematic Map. Lines demonstrate the interconnectivity between main themes and subthemes.

One participant reflected on how a lack of knowledge and training leads to sexual issues being dealt with “when they arise” rather than raising it more pro-actively:

P5:2 It's more a case of dealing with things isn't it when they arise... It's like {P7:2 name} says, we're not trained in that area to discuss sexual issues (.) or sexuality with people so- So if those issues do arise it's obviously dealt with- with the individual at the time

When talking about the sexuality issues, there was a tendency amongst participants to make a distinction between the “mechanics” or “plumbing and wiring” aspects of sex, and the more emotional or interpersonal problems. Participants tended to feel more knowledgeable and thus comfortable with regards to one area as opposed to the other, as highlighted in the extracts below:

P3:1 I think with mechanical problems are easier to look at sometimes. Personality and relationship changes due to changes from the head injury (.) are incredibly difficult

P7:4 It would probably, like, depend on what aspect, like if it was more of a medical sort of thing that was brought up, I as an OT wouldn't feel confident commenting on that. I'd then go and ask a doctor or nurse maybe to speak about it

The participant in the latter extract highlighted that she would consult a doctor or nurse with regards to issues that she felt less confident to deal with. Indeed, participants across all four focus groups highlighted the ***'Importance of consultation, supervision and teamwork'*** in addressing or planning to address sexual issues with service-users. Some participants felt that this approach would enable them to manage their lack of knowledge and/or expertise. For example:

P5:2 So if those issues do arise it's obviously dealt with...and if there's any (.) erm (.) any reason why we don't think we can, then we go and ask somebody else ((sounds of agreement from others)) their advice on it.

So, there's- y'know, people come in and it's not just you- y'know you don't just feel like you're on your own doing it

In the following extract, P4:1 suggests that deciding to consult other professionals as a result of a lack of knowledge may have a negative impact on the service user. However, P2:1 then challenges this notion:

- P4:1 That doesn't always feel comfortable because if they felt they could open up to you and then you say you don't know but I'm going to go and ask somebody else. It doesn't make- I presume it doesn't make them feel great
- P1:1 Well [it-
- P4:1 [Well perhaps it might
- P2:1 Well if you say, y'know, I'm not the expert in this field but I have got somebody I can discuss it with, do you mind? I think it's-
- P4:1 Yeah
- P2:1 I'm still offering to support them and find out for them
- P4:1 Yeah, Yeah. And that's the way we work. We often say, oh I don't know about that, I'll find out and come back to you, so that's [part-
- P2:1 [And
that was the role in the early days, especially the role of case manager. You might not know all the answers but we know, y'know-
- P4:1 Somebody [who does
- P2:1 [We can go and find out for you, that sort of thing

As a result of P2:1's challenge, P4:1 shifts her initial position. The participants then reach consensus that it is acceptable to consult other professionals with regards to sexual issues when required. The participants therefore indicate that 'not knowing' should not necessarily form a barrier to asking about sexual issues. Indeed, a participant in the same focus group later reflected on how "sometimes they ((service-users)) just want to list their problems...knowing that there's not always an answer" (P3:1).

Several participants spoke of occasions where they had consulted members of their team for advice on managing sexual issues. Reflecting on a personal experience, one participant talked about the usefulness of accessing external supervision from a specialist sexual health clinic. However, a difficulty in using

this as a formal arrangement was highlighted given the perception that sexual issues don't rise frequently enough:

P1:1 I've had some contact with some people at the {name of clinic} erm looking to get some support or some supervision on those issues ((hypersexuality and erectile dysfunction)), but it's hard to get a regular arrangement with that because A, maybe we don't ask the question enough, but err those problems don't arise often enough for me to have regular contact with them...So it's become more of a sort of informal arrangement. I might phone somebody once every two years

Participants across three of the focus groups identified that further '**Education and staff training**' would enable them to feel more equipped in dealing with the complexities of sexual issues after TBI. However, the participants within some of the participants that were aware of training available through their organisation identified that they had not accessed it or did not think that it would be particularly useful given the more advanced level of training perceived to be required. One participant reflected on a potential limitation of training, stating that it wouldn't necessarily address feelings of "uncomfortableness" amongst professionals (P4:1). This participant suggested that role plays, to practise talking to patients may be helpful, particularly at an early stage in professionals' training.

Only one participant explicitly disagreed with the notion that sexuality after TBI is a specialist subject. He drew on his own personal experience of working with a service-user who was experiencing erectile dysfunction to come to the conclusion that "it's not rocket science...it's not all that mystifying after all" (P1:1). However, it is important to note that the management of sexual issues does not only include erectile dysfunction, and that sexual difficulties span the entire spectrum of sexual responses.

3.3.1.2 Sexuality is a sensitive subject

Firstly, some participants expressed the viewpoint that raising the issue of sexuality may be perceived as intrusive or inappropriate to service-users, which led to some staff wondering if this may “scare them off” (***Risk of offending the service-user***):

- P4:3 I think the problem would be that they'll shut down, or they'll struggle to, y'know, get that good relationship going so that we can get them participating in rehab.
- P1:3 Yeah [Yeah ((indicating agreement with P4:3))
- P4:3 [If you scare them off on the first few [visits then-

P4:3 above highlights that there may be a potential risk involved in asking about sexual issues too early, thus creating a dilemma regarding '*The best time to raise sexual issues*'.

Related to this, the participants in one focus group hypothesised that those from “different cultures” and religion would be more offended. The extract below illustrates how the discussion began by P1:1 posing a question to the rest of the group. It is clear that the other members of the group had not previously thought of this idea, however, they then begin to understand and expand on this:

- P1:1 Are there people from different cultures that we would feel less comfortable about asking about sexual relationships?
- P2:1 That's interesting
- P4:1 That's a really good point because there [is
- P5:1 [Religion makes a difference as well doesn't it?
- P1:1 Yeah
- P4:1 Yeah (.) I think it shouldn't, but I guess it does.
- P1:1 Well I guess it's a moot point whether it shouldn't, because I guess some people of different cultures and religions would be more offended
- P5:1 Yeah, yeah they would

P4:1 Well I don't know to be honest, do you know what I mean? I presume that, but I actually don't know. That's- I wouldn't because I have that presumption but I'm not sure where I've got that from

Related to this concern about appearing intrusive and potentially offending the service-user, participants wondered about how best to raise sexual issues with service-users. One participant stated that you have to “make sure that you're not coming across in a manner which would be seen as unprofessional” (P1:2). Some participants felt that '**You can't ask about sexuality directly**', instead “subtly taking opportunities” (P1:3) to discuss sexuality. However, one participant challenged this notion that you can't talk about sexuality directly, giving an example from his own practice:

P5:4 I'll give you an example about a patient I had here...I talk about physical aspects continence or something, and then mention (.) there are issues about sexuality. If you feel that at any time that this issue is important and you want to discuss, please feel free to contact me or contact the ward or something. So at least- ((sounds of agreement from others)) I open the subject, I leave it to them

3.3.1.3 Practicalities of discussing sexuality

Participants across all four focus groups discussed the potential use of '**Formal assessment tools**' to facilitate discussion about sexual issues. One participant suggested that a questionnaire might enable professionals to “surreptitiously” bring up sexual issues with service-users:

P4:1 I think a routine- I think one way is having a standardised questionnaire where it's brought up, like the EQI. The European, what is it? The-

P1:1 European Brain Injury Questionnaire?

P4:1 Yeah I think it's on that, so I think having something like that. What I was thinking, when I was thinking about this was that if I think it's an issue, a way around surreptitiously...bringing it up. It's there as a question, so then it gives them permission to ask it...that might be a way of raising their awareness that there is a whole gannet of

problems because often people don't realise that the problems that their experiencing are related to head injury sometimes

P4:1 above highlighted that a questionnaire may raise awareness amongst service-users of the sexual issues that can arise, and also grant "permission" for service-users to ask about any sexual concerns they might have. The participants in FG3 agreed that a questionnaire can provide "an opening" to ask about sexual issues, however they also highlighted that the questionnaire used in their service had not been particularly successful in facilitating discussion, as "they just tend to leave it blank" (P1:3).

When considering why service-users might not respond to this question, participants generated a number of hypotheses: "it's the first meeting with the professional and they might want to discuss it with someone they know well", "it's not high on their priority" (P1:3), "they think that's not why they're here" (P1:3), they might not want to bring private husband-wife relationship issues into a TBI context (P3:3), or because they often attend their first session with someone somebody else who they don't want to discuss it in front of (P3:3). When reflecting on what could be done to overcome this, one service-user suggested that you could ask service-users directly, however, she immediately followed that with "but I wouldn't be very good at that". Indeed, a participant in another focus group reflected on how a questionnaire may be used as a "shield" by professionals to avoid approaching sexuality issues more directly (*'You can't ask about sexuality directly'*):

- P1:1 I think I'd also argue that err, and I'm probably guilty of this one as well that in a sense it's a bit like hiding behind a questionnaire
- P4:1 Yeah. Yeah. Yeah ((indicating agreement with P1:1))
- I: Mmm
- P1:1 It's like a sort of shield really
- P1:1 to hide your own embarrassment or potential discomfort
- P4:1 Yeah ((indicating agreement with P1:1))

During the discussions, participants wondered about ***the 'The best time to raise sexual issues'*** with service-users. Firstly, some participants said that

they tend to take the lead from the service-users rather than initiating discussions themselves:

- I: Do you think that it is a role that health professionals should discuss sexual issues?
- P1:3 Yes I certainly do. But erm we tend ((says slowly)) to let them make the opening gambits

Some participants expressed the viewpoint that sexual issues would not be an appropriate topic for discussion at an initial interview, for example one stated “you have to collect that information gradually” (P4:3). Participants highlighted two main disadvantages of asking about sexuality issues too early, leading to a general opinion that it is better to wait until later in the rehabilitation process. Firstly, and as discussed earlier, some participants felt that asking about a sensitive issue too early may offend the patient and damage the therapeutic relationship (*‘Risk of offending the service user’*). One participant drew on her personal experience of working within another setting to construct this argument:

- P5:1 I think having worked somewhere else where on their initial assessment there was a question that kind of alluded to- but I think it almost shut people off
- I: Right
- P5:1 Because it was so- they came for their first sessions so lots of them had perhaps been diagnosed perhaps with something new and so obviously their world was upside down and you’d go in there and they’d perhaps be sat there with their partner, they’re world’s been turned upside down and you’d ask a question like that, it almost felt like the doors shut on you and they’d kind of withdraw. Because it was inappropriate to be asking at such an early stage I think

Secondly, participants felt that service users may be unaware of the sexual problems that arise, and thus discussing it with them it may cause them extra anxiety:

- P4:1 But I think it depends on who that person is, because some people-
- P2:1 Are likely to get hung up on it
- P4:1 Pardon?
- P2:1 Are likely to get hung up on it. If you present it as a possible problem then some people do start worrying about it. You've got to let it take its natural course. It will be like 'when's it gonna happen', 'when's it gonna happen'

The third subtheme relates to the participants discussions regarding '***The best setting to discuss sexual issues***'. Firstly, one-to-one time between professionals and service-users were seen to facilitate discussion. Participants across two focus groups highlighted that a service-user's parents being present during an initial assessment would hinder discussion about sexual issues: "sometimes we don't ask it if maybe they're sitting next to their parents getting the assessment done, because it's just, out of respect" (P6:2).

Another participant (who works across both inpatient and outpatient settings) commented that he tends to discuss sexual issues more frequently in the latter setting given the increased opportunities for one-to-one and privacy (P5:4). The extract below also demonstrates the importance of seeing people 'one-to-one':

- P4:1 Going back to the barriers, I was wondering the opposite way. Things that may help. We sometimes see people in their own homes or where they feel comfortable
- I: Yeah
- P4:1 And often on a one to one. Whereas if they come in for a clinic review they're in that sort of hospital building with a lot of people and that becomes a barrier
- I: Mmm
- P4:1 But conversely going out and talking to them at home or-
- P2:1 With a cup of coffee on the settee-

The participants in the extract above highlighted that seeing people in their own home, "where they feel comfortable" may facilitate discussion about sexual issues. However, concerns were raised with this as some participants felt that they may be making themselves more vulnerable to accusations (P1:1) or the service-user sexualising the meeting (P5:1) ('*Professionals may be vulnerable*').

Some participants felt that non face-to-face interaction may be the best setting for sexuality to be discussed. One participant suggested that “something like computer programmes...would be more beneficial” (P3:2), whereas the participant in the extract below reflected on the potential benefits of service-users utilising an established helpline for sexuality advice. The agreement from the other participants in the focus group is indicative of a shared viewpoint:

- P4:3 You ring up and they can give you advice on a range of things associated with head injury, and I think that's- I think that must be nicer for clients because-
- P1:3 Yeah ((indicating agreement with P4:3))
- P4:3 It's confidential and you haven't got to ((sounds of agreement from others)) sit in front of somebody, and explain to them. But they might be able to give you advice on what to do next

Participants in three of the focus groups spoke about the potential merits of discussing sexual issues in a group setting. One participant used her own personal experience of facilitating a group to reflect on the potential benefits of peer support:

- P4:2 ...there was one time where someone was saying he getting really frustrated and upset that he couldn't get a girlfriend and stuff like that, and he said it out towards the group and the group said basically towards him, like, well look you don't have to worry about it, you'll find someone...And it's much better for them to hear it from people that have also had a brain injury, than someone in a professional role trying to say that to them, and I think it meant a lot more to him

However, potential difficulties of discussing sexual issues in a group setting were also raised. Firstly, one participant pointed out that “being given information by a service-user isn't very good”, arguing that any group sessions would need to be carefully managed by professionals (P1:2). Secondly, one participant suggested that “it's not something that people want to discuss in a group setting” (P1:3), the assumption being the sensitive nature of the topic. Thirdly, one participant reflected on how it could potentially be difficult to

administer a psycho-education group in a TBI setting (as opposed to service-users with spinal injury) due to the variation in the service-users' presentations:

P5:4 The problem with traumatic brain injury, it differs from spinal - spinal
 their brain is usually is intact, and their needs have got a lot of
 similarities. We can use a sort of discussion- but with traumatic
 brain injury, every patient is totally different

Participants across three focus groups discussed the potential benefits of having information readily available in their working environment, either through information leaflets (FG1, FG3, FG4), a notice board (P1:3), “or even a sign saying it’s okay to ask” (P4:3) (***‘Providing written information’***). Indeed, one participant commented that “the biggest barrier is that when patients come here, they don’t really think it’s on the agenda” (P4:3). However, some potential problems with this strategy were identified. Firstly, one participant commented; “well I ordered the leaflets and that’s not to choose from. If I could order it, I would” (P1:3). The same participant was also concerned about having leaflets about sexual issues readily available given their expense to the service:

P4:3 But then again err you can’t really [have it in the waiting area (*laughs*)
 P1:3 [I know, I was going to say, I can’t
 afford my three pounds fifty to just disappear, untargeted almost

Participants in another focus group discussed the possibility of amalgamating written information about sexual issues into other information routinely given to service-users. For example, one participant suggested adding a page about sexuality in the service’s booklet to raise awareness of the potential issues that could arise (P2:1). However, in response to this, one participant questioned whether this is just “another means of preventing it ((discussion about sexuality)) as you don’t have to mention it verbally” (P1:1).

3.3.1.4 Roles and responsibilities

Only one participant explicitly expressed the view that discussing sexuality is not part of their role, stating “I don’t think it’s in our job description to do that to be honest” (P4:2). However, other participants did express this viewpoint more implicitly. For example, participants in an inpatient setting did question whether their team is best suited to discuss sexual issues given that sexuality is not usually a priority until ‘later down the line’ (*‘Sexuality is side-lined in rehabilitation’*). Instead, they were of the opinion that the local community based teams would be better suited to address sexual issues.

When discussing who the best person would be to have discussions about sexuality with service-users, several suggestions were made by the participants. Across the four focus groups, participants suggested that it should be the occupational therapist’s role, the medical consultant’s role, the psychologists’ role, the case manager’s role, the cognitive-behavioural therapist’s role, and medical physicians role (for the more “physical aspects”; P5:4). Participants in one focus group identified that the best person to take on this role would be a “specific counsellor” who has been specifically trained in sexual issues, again representing the viewpoint that *‘Sexuality after TBI is a specialist issue’* which requires specialist *‘Education and training’*. However a potential limitation of relying on this was identified: “realistically, because of the way funding works and things like that kind of thing would have to cover a whole range of things including that” (P6:2).

Furthermore, several difficulties were identified by the participants with regards to allocating a specific person to address sexual issues. Firstly, there was recognition amongst the participants that there are a widespread range of sexual issues that can arise following TBI, and therefore they identified that it largely “depends on what the issue is” (P2:1). Secondly, participants felt that the management of sexual issues need not be the responsibility of one professional alone, given the high value that they placed on teamwork (*‘Importance of consultation, supervision and teamwork’*). Finally, participants felt that it should be the service-users’ choice who they decide to raise sexual issues with.

Indeed, participants across three focus groups identified that the development of rapport through the *'Therapeutic alliance is important'* in facilitating communication about sexual issues after TBI. Some participants discussed the therapeutic relationship in terms of the amount of time that the professional and service-user have known each-other:

- P1:3 ((to P4:3)) Do they tend to talk to you about it rather than [you-
P4:3 [Ooh it takes
a long time for it to get there. Erm, I can only think of a couple of
examples where people have finally trusted me with that gem of
information....and yeah, they definitely won't talk about it within the
first, sort of, six to eight sessions

However, some participants highlighted potential problems with relying on the professional with the best therapeutic relationship with the service-user to communicate about sexual issues. Firstly, the participants in one focus group suggested that a well-established therapeutic relationship may actually hinder communication about sexuality. When comparing the following extract to the extract above, it is evident that P4:3 could see positive and negative aspects of a well-established therapeutic relationship:

- P1:3 I mean we know them very very well by then, and maybe we know
them too well
P4:3 Yeah, and then I think we've got a familiarity there and you don't really
want to- ((makes hand gesture of pushing away))

Secondly, another participant questioned whether a close therapeutic relationship may actually make the professional more vulnerable (*'Professionals may be vulnerable'*):

- P5:1 But then if they feel that comfortable with you, does that then make
you then vulnerable? You know, is that when it could be- They feel
that comfortable to say that to me, but then is that then putting me in a
position of, I need the front door urgently

Thirdly, one participant identified how the formation of a long-term therapeutic relationship between a professional and service-user is not always possible in healthcare settings:

P1:1 ...and that's not something that's common in healthcare. Less common in healthcare is having a consistent long-term relationship with a therapist or practitioner I think

When reflecting on who is the best person to discuss sexual issues with service-users, some participants expressed concerns about giving advice about sexuality when there is a '**Gender mismatch**' between professional and service-user, as shown in the extract below from a female participant:

P3:2 ...Also it's difficult in itself to deliver it in quite the right manner, and also it depends on who delivers it as well, especially if you've got male service users and a female delivering it, it could be quite [difficult
P1:2 [Tricky
P3:2 Yeah

A male participant from the same focus group shared this view regarding giving advice to service-users of the opposite gender:

P1:2 I don't think I could give information as well as a female to a female on the subject of that- I just don't think I could. No- That's something that I would- not try and steer from- but something that I would pass on to a female member of staff
I: Okay (.) Why do you think it's better coming from- better coming from someone of the same sex?
P1:2 Same body parts. You can relate to it more. As I was saying, I wouldn't be able to give-
P3:2 Yeah
P1:2 Give genuine advice on problems that maybe a female would

3.3.1.5 Dilemmas about risk and vulnerabilities

Some participants were concerned about the potential risks of '**Abuse and exploitation**' involved with service-users expressing their sexuality. For example, the participants in one focus group (FG3) raised concerns that accessing nightclubs, the phone book and the internet in order to meet potential sexual or intimate partners, could potentially place service-users in vulnerable situations.

However in contrast, some participants argued that service-users should be allowed the opportunity to express themselves sexually, despite the potential risks involved. In the extract below, P1:3 initially indicates that she is comfortable with the knowledge that a service-user is engaging in sexual activity, "as long as he's not placing himself at risk". However, this is then challenged by P4:3:

- P1:3 I mean, this week he said I've decided I'm going to have a bit of fun while I'm looking, which again, is a young man's attitude to sex
- P4:3 Yeah ((indicating agreement with P1:3))
- P1:3 So (.) as long as he's not placing himself at risk (.) although he's out all night, I mean, I don't *know where he is* or what he's doing-
- P4:3 Yeah but then again it's a lifestyle choice isn't it, I'm sure-
- P1:3 It is, yeah
- P4:3 Young men without head injuries probably place themselves at risk
- P1:3 Oh yeah
- P4:3 (*laughs*) quite regularly. Should we deny him that opportunity for that bad behaviour?

P4:3 argues that casual sex is a "lifestyle choice" that many "young men" engage in. Underpinning this is a view that individuals who have experienced a TBI should not necessarily be treated differently from people in the general population, because of their injury. Indeed, a participant in another focus group highlights this:

- P1:1 That's an interesting point actually. Y'know, if someone was promiscuous before their injury, are they then perceived as being

sexually vulnerable afterwards because of their head injury, when their behaviour might not have changed at all

Related to this, the participants in one focus group reflected on the challenge of working with a service-user who wanted to access paid-for-sex, given that a “person without a head injury can go to prostitutes” (P4:1), whilst another participant reflected on a personal experience of working with a service-user at time when “it was discovered that he’d been downloading porn” (P1:1). The participant indicates that he could not understand why some participants were so “outraged” at a service-user accessing pornography, given that the service-user was only doing “what 99.9 per cent of other teenage lads in their twenties were doing” (P1:1). Of course situations such as these raise a number of moral, ethical and legal dilemmas for the professionals involved in these service-users care, and professionals’ own personal attitudes are likely to have an impact on how they respond. In the latter case, P1:1 reported that there were gender differences in the reactions of the professionals’ involved in this service-user’s care:

P1:1 The men involved in this...were more concerned about him potentially viewing inappropriate things and getting himself into trouble, spending money on the internet, err getting into trouble with credit card cloning and stuff like that. And were less morally outraged by what he was doing. But the women involved in this guy’s care were horrified that he was viewing porn because it sort of dehumanises women and sees them as y’know sex objects rather than people and things like that, which is a real issue, yes

Participants also discussed that ***‘Hypersexuality and disinhibition’*** can create risks in some individuals who have experienced a TBI (participants mainly referred to males). During the focus group discussions, participants made reference to instances where service-users have made inappropriate sexualised comments and sexual advances towards staff and other service-users, as well as more general “rowdiness” and “sexual banter” (FG3). There appeared to be a tendency amongst professionals to address sexual issues with service-users only when their behaviour is perceived to be inappropriate. For example, one

participant reflected on how in the past sexually inappropriate behaviour has been managed by professionals, whilst neglecting to discuss with the service-user “what is appropriate behaviour” alongside this (P6:4). The implication of this is that discussions about sexuality tend to be reactive, rather than proactive.

Some participants felt that service-users should not be blamed for hypersexualised or disinhibited behaviour, an assumption which underpins the following dialogue:

P4:2 And also they could end up in trouble. Really big trouble. They could end up even being arrested or whatever without even knowing the line that they've crossed...and that's not fair for them. Cos they're just another person in the- in the law's eyes. It's not- But they just misinterpret them, that's what they do

The participant in the extract above indicates that there may be a risk of sexualised behaviour being misperceived by other people, which could lead to negative consequences for the service-user. Indeed, participants felt that there is a lack of awareness, and sometimes “shock and surprise” (P1:1) amongst staff in other, non-TBI, settings that people with TBI can be disinhibited.

However, one participant challenged discussions about sexual disinhibition and inappropriate sexual behaviour, arguing that this does not apply to the majority of service-users. The agreement from the other participants during the following indicates some level of shared understanding:

P5:4 I- I think that the issue that many staff have, is difficulty appreciating that- We are always relating sexuality after TBI to sexual disinhibition or behaviour ((nods from others)) But if anything, this is only a minority of patients that will have this

The next subtheme relates to the concern amongst participants that professionals may be placed in a vulnerable position (***‘Professionals may be vulnerable’***) as a result of discussing sexuality issues. This subtheme is highlighted in the following dialogue between participants:

- P1:1 I guess I'm thinking another potential barrier that has crossed my mind on occasions...Being a bloke. Working with female clients on issues of mood for example, erm, in the clients home. It might seem a bit of a erm (.) I guess I would occasionally worry about how it would be perceived if I were to ask questions about sexual relationships and sexual function in that context...and I suppose whether it will be safe, whether that might be misconstrued
- I: Mmm
- P1:1 as being like a lone worker, male lone worker in a female client's home. So that is a potential barrier to asking a question I guess, and probably has (.) Erm [crossed my mind
- P4:1 [Interestingly I don't find that so much the opposite way round
- P5:1 I do
- P4:1 [Do you? ((sounds surprised))
- P5:1 [I do. Most of the people that we work with are similar to my age aren't they? So if I was to say, like {P1 name} just said, I might feel similar. That I would be putting myself in a position of vulnerability
- P4:1 Maybe that's an age thing then. Maybe that's 'cos (.) I'm older
- P1:1 Perhaps it might be rarer for male to accuse- *make accusations against female therapists (laughs)* ((laughter from others)) But that would be one concern, about being accused of talking about stuff that was inappropriate

The extract above suggests that whilst there was some agreement between P1:1 and P5:1 on the belief that they might be placing themselves in a vulnerable position by discussing sexual issues, different positions are taken on what that means. The male participant (P1:5) wondered whether by discussing sexuality issues, he may be putting himself in a position where he is more vulnerable to accusations due to discussions being 'misconstrued'. The female participant highlighted her concern that raising sexual issues with (male) service users of a similar age may put her in "a position of vulnerability". She seems to be suggesting that service-users may sexualise the consultation or make inappropriate advances, particularly as she later highlights her concern about needing "the front door urgently" (P5:1). However, P4:1's surprise at this disclosure indicates that this is not a feeling shared amongst all female

participants. Interestingly, participants spoke about the possibility of these events in the context of working with service-users of the opposite gender. Participants did not seem to feel the same way about working with service-users of the same gender, which perhaps is also indicative of an assumption of heterosexuality.

Related to this, one participant expressed concern about discussing sexual issues for fear breaching his employment contract. After presenting the opening question to the participants in FG2, the participant in the extract below immediately responded with “Err yes, but...” Although initially perceived as a token of agreement, it becomes clear that the participant is reluctant to discuss sexual issues:

- I: So do you think that staff like yourselves who work at {organisation name} should discuss sexual issues with clients?
- P4:2 Err yes, but only on a- you see it's the err- laws and legislations- It's a thin line isn't it so it's like, you don't want to be breaching any of your contract if you know what I mean- your contract, so it's hard to get into depth about something like that

3.3.1.6 Organisational and structural factors

Many professionals felt that organisational constraints prevented them from raising sexuality with service-users. Participants raised concerns about opening up communication about sexual issues, when there is a lack of (or at least a lack of awareness of) available specialist services to refer service-users on to (***'A lack of specialist services'***). Participants that did discuss the specialist services that are available in the local area were sceptical about whether they would be able to provide an appropriate level of support given the complicating factor of the service-users' TBI. For example, one participant comments that “normal marriage counselling” may not be successful when one partner has experienced a TBI, as it “isn't going to address the neurological side of it” (P6:4).

Indeed, participants in another focus group commented that when they had referred people with TBI to a relationship counselling service, this had not been particularly successful in tackling the relationship difficulties. One participant reflected on how a specialist sexual health service is not “geared” towards working with people with TBI due to the complex nature of their condition:

P1:1 I think it's one of the problems really. That y'know it feels like if you ask it, if you ask the question, then you're probably going to have to deal with it yourself because these services have a massive long waiting list and they'll offer one session for a bit of information and advice. Y'know (.) is that gonna help somebody that's had a moderate or severe head injury?...They're not geared for working with people who have different needs to your average erectile dysfunction, where they come in, having done a lot of research on the internet, having been to the doctors and had discussions. And not having any memory problems and all those kind of issues

The participant in the extract above highlights that “if you ask the question, then you're probably going to have to deal with it yourself”, a perception which could prevent professionals from opening up the perceived ‘can of worms’. However, one participant challenged the notion that there is a lack of services available for people requiring support in this area, indicating that professionals do not need to be able to offer interventions to be able to raise sexual issues:

P5:4 ...We never- never claim that we are trying to give therapy or intervention, but what we can do at least is screening for it, identify who needs somebody for something, and then there is many organisations who are able to do it. The problem I think, the bottleneck is that nobody is approaching this aspect.

The second subtheme relates to how sexuality is side-lined in healthcare due to organisational pressures relating to a lack of time and resources (***‘Sexuality is side-lined in rehabilitation’***). The following extract illustrates that a dilemma could arise for professionals when there is a conflict between their own agenda and that of the service-user:

P1:3 But it's costing a lot of therapy time...I don't really want to discuss- An hour's worth of discussing who he's broken up with, who he's slept with, who he's seen in the street, who he fancies. We're more interested in, y'know, err is he budgeting properly? Is he- but that's what he's budgeting on ((laughter from others)), so you know it's really difficult because part of me feels that I shouldn't be wasting my (.) time, but that's what makes him tick

The participant's reference to "budgeting" in the extract above suggests that she believes that there are more pressing problems to discuss and address than the service-users' sexuality and recent relationships, which he apparently does want to discuss in their sessions.

However, generally the side-lining of sexual issues for more "pressing problems" was not seen as problematic by the participants. This was for two main reasons. Firstly, some participants expressed the viewpoint that sex is not viewed as a priority for service-users in the context of their other problems, and thus they "focus on the things that they want to focus on"(P1:3). This is also highlighted in the two extracts below:

P4:3 And again it's about priorities. If they can't walk down the street (*laughs*)...That's something you want to work on before

P4:4 ...it's not something that comes up very often from the patient...I think if they're coming along to a specialist service often they've got more pressing problems, and it's more of a secondary thing, so we tend to focus our resources on the most pressing problem at that point

The latter extract also highlights the assumption amongst some professionals that because service-users don't raise sexual issues, it must not be a problem for them or they must not want to discuss it.

Other participants did not view the side-lining of sexual issues as problematic given that some interventions may have indirect effects on sexuality. For example, one participant commented that sexually demanding behaviours "often will settle down once somebody's making improvements" (P1:3). In

addition, some participants also commented on service-users who report (via a questionnaire) that they are less interested in sex following their TBI:

- P1:3 I think, when they tick the less one, it's more to do with fatigue. Erm-
I: Mmm
P4:3 In which case they don't need direct [treatment for that problem-
P1:3 [Yeah, no
P4:3 They need treating for the fatigue

Related to this subtheme of the side-lining of sexuality for other issues, participants across two focus groups pointed out that within the context of their organisation, sexuality is not included on routine measures of functional and rehabilitation outcome (***'Sexuality is not included on outcome measures'***):

- P5:4 I think the other thing is that we're more overwhelmed with outcome measures- ((nods and sounds of agreement from others)) and other things, and there's nothing in the outcome measure about sexuality or quality of life in general. There is an outcome measure if the OT discharged someone who had a fall, or if somebody escaped or something, because the next day there will be a risk management and it would be clinical incidence, but there's nobody who will err- who will take us to court because this has not been discussed or not been addressed

The participant above presents the hypothesis that sexuality is not discussed because there are no measurable consequences for professionals that do not address sexuality issues. Although this subtheme was only highlighted by one participant, there were nods and sounds of agreement from other group members during the exchange. The reaction of the group members to the phrase "we're more overwhelmed with outcome measures" indicates a shared reference, and one which perhaps has a significant influence on the team.

Finally, some participants felt that the '***Clinical environment of the hospital setting***' may hinder communication about sexual issues. Firstly, one participant commented that within an inpatient setting, there are often little opportunities for one to one and privacy between professionals and service-users (P5:4).

Secondly, another participant felt that the inpatient setting may prevent service-users and their partners from realising that there has been a change in their relationship or sexuality.

P6:4 I guess it's not the physical aspect, it's sort of how close the couple is and y'know the emotional side of it and they might not know until they're at home twenty four hours a day after a couple of weeks when they think, y'know, something's different. They probably don't realise, because it' so clinical here they probably don't notice the- the change in their relationship until (.) when they're home and you expect normal service to resume and it doesn't. So maybe, you know, I think outpatients and community teams probably have a big role to play there

This stance could potentially prevent professionals in inpatient settings from discussing sexuality following TBI, if they make the assumption that they haven't had the opportunity to 'test it out'. This may lead professionals in inpatient teams to shed responsibility of sexual issues, believing that outpatient settings are better suited to address sexuality issues (as illustrated in the extract above). However, in this focus group a disagreement arose. One participant argued that "on the other hand, many of our patients go for graded discharge" (P5:4), indicating that service-users do in fact have the opportunity to have time away from hospital. Hence, the inpatient setting should not necessary prevent professionals from raising sexuality issues with service-users.

3.4 **EXTENDED DISCUSSION**

This section expands on the journal paper by embedding the results within the context of previous research findings and psychological theories to explain some of these findings. Suggestions for clinical practice, training, policy and future research are made. This study will then be critiqued, and close with the researcher's critical reflection.

3.4.1 **FURTHER INTERPRETATION OF ANALYSIS**

Each of the six main themes will be discussed below, with reference to previous literature. For ease of reading, themes have been separated out. However, as depicted in figure 5, themes often overlap.

3.4.1.1 **Sexuality after TBI is a specialist issue**

Participants cited inadequate knowledge, skills and expertise (perceived or actual) as major obstacles to communicating about sexuality issues with service-users after TBI, a barrier which was raised over twenty years ago (Ducharme & Gill, 1990). Perhaps unsurprisingly, professionals viewed education and training as a factor that facilitates communication about sexuality, supporting previous research from TBI settings (Davis & Schneider, 1990; Haboubi & Lincoln, 2003; Hough, 1989; Katz & Aloni, 1999), and also from other healthcare settings (Humphery & Nazareth, 2001; Juergens, Miller Smedema, & Berven, 2009; Lewis & Bor, 1994; McLaughlin & Cregan, 2005; Nnaji & Friedman, 2008; Rubin, 2005; Stokes & Mears, 2000). Unfortunately, research indicates that there are minimal training opportunities available for professionals interested in increasing their knowledge about sexuality after TBI (Davis & Schneider, 1990; Haboubi & Lincoln, 2003).

Sexuality training has been shown to increase sexual comfort amongst professionals (Katzman & Katzman, 1987; Post, Gianotten, Heijen, Hille Ris Lambers, & Willems, 2008; Simpson, Anwar, Wilson, & Bertapelle, 2006; Yallop & Fitzgerald, 1997) and promote more positive attitudes toward sexuality

(Katzman & Katzman, 1987; Post et al., 2008). Sexuality training has also been found to increase willingness to discuss sexuality (Novak & Marlys, 1988; Post et al., 2008), with some findings expanding on this by indicating that comfort with sexual issues acts as an intervening variable between sexuality training and willingness to discuss sexuality with service-users (Juergens et al., 2009; Novak & Marlys, 1988). One psychological theory that can be used to explain this is self-efficacy theory, which asserts that all forms of behavioural change operate through a common mechanism: The alteration of the individual's expectations of personal mastery and success over the behaviour in question (Bandura, 1977, 1982). Professionals are unlikely to perform a task if they believe they will be unsuccessful. In contrast, if professionals believe that they can successfully address sexuality issues, this will affect their motivation to address such issues, as well the effort expended, and their persistence in the face of adversity (Bandura, 1977).

3.4.1.2 Sexuality is a sensitive subject

The belief that raising sexuality issues could offend service-users may prevent professionals from entering into conversations about sexual issues. Other researchers have also reported that the likelihood of a professional discussing sexuality will be influenced by expected responses from service-users (e.g. Schnarch, 1981). Similarly, Kautz, Dickey, and Stevens (1990) found that "discussing sexuality causes the patient anxiety" (p. 74) was the most common barrier reported by nurses when addressing sexual concerns. Indeed, if professionals believe that the professional – service-user relationship is based on trust and geared to promote comfort and well-being, then professionals may 'protect' service-users by avoiding discussion of topics that might elicit a negative effect, such as discomfort or anxiety (Magnan, Reynolds, & Galvin, 2005). This could also be understood from a behavioural perspective: Avoiding raising sexual issues acts as positive reinforcement as professionals perceive that it enables them to maintain positive relationships with service-users. It could also be argued that avoidance simultaneously acts as negative reinforcement, as it enables professionals to avoid the aversive feelings associated with asking about sexuality.

Some professionals wondered if people from “different cultures” and/or religions would be more offended by questions pertaining to sexual issues, but did not specify which groups they were referring to. However, from their discussions, it was assumed that they were referring mainly to non-white, non-European individuals. This finding is consistent with what professionals working in other healthcare settings have identified (Gott et al., 2004; Hordern & Street, 2007). It is important to consider that decisions not to initiate discussion may be based on pre-existing beliefs and stereotypes of how professionals think people will respond, rather than direct personal experiences (Dyer & das Nair, 2012). For example, one GP in Gott et al.'s (2004) study reported feeling surprised that Pakistani women were ready to discuss sex.

However, there is some evidence that talking about sexuality is more taboo amongst Latina women and Asian-American women than amongst white Americans (Katz, 2002), with research indicating that both groups respond to discussions about sexuality more positively after a more informal period of “small talk” (Davis, 1996; Noeranger Stern, Tilden, & Krassen Maxwell, 1985). This suggests that a more forthright method, such as through the use of a questionnaire may not be favourably received. However, no one group is homogenous, and it is therefore important not to stereotype or profile a person because of their racial or ethnic group. Perhaps a more useful approach would be to have several options for service-users to select from in terms of how they would like sexuality issues to be raised.

3.4.1.3 Practicalities of discussing sexuality

Professionals in the current study identified that formal assessment tools would enable them to communicate about sexual issues more proactively. Ducharme (1994) recommended that sexual histories are taken from all service-users as a regular component of the rehabilitation. However, this may be unnecessarily intrusive given the sensitive nature of much of the information collected, alongside the fact that a substantial proportion of people with TBI do not experience sexual disturbance (Simpson, 2001). Another approach is to

incorporate one or more questions about sexual interest and functioning into a routine battery of questions about various areas of psychosocial functioning, which would provide people with TBI the opportunity to raise any sexual concerns (Simpson, 2001). This may also help to create a more facilitative environment which grants 'permission' to service-users to raise sexual issues with the professionals working with them. If a sexual health concern is then identified, there are also a number of more specific, in-depth assessment tools available. Brain injury specific measures include the *Psychosexual Assessment Questionnaire* (Kreutzer & Zasler, 1989) which was developed to assess the functioning of males with TBI, and the *Sexual Interest and Satisfaction Scale* (Kreuter et al., 1998), a gender-neutral questionnaire where the respondent self-rates sexual desire, sexual ability, the priority they give their sexuality and their level of sexual satisfaction. These tools are more descriptive than diagnostic *per se*, but can identify where further assessment and treatment is required (Simpson, 2001).

Professionals highlighted the potential advantages of having written information available for people with TBI and their family members, which has also been highlighted by Simpson (2001). The most comprehensive way to do this would be to provide service-users with sexuality-specific information resources, such as those already available (Dawson, Hendy, Simons, & Epps, 1999; Griffith & Lemberg, 1993; Simpson, 1999). However, given the concern about the cost of reproducing or purchasing these, it may be more feasible to include sexuality issues within information booklets addressing the more global impact of TBI (Gronwall, Wrightson, & Wadell, 1996), or to refer service-users and their family members to relevant websites (e.g. www.outsiders.org.uk; www.thedtgroup.org/brain-injury.aspx). It would of course be important for any written information to be adapted for TBI populations. Ideally this should involve all literature undergoing pre-publication screening where legibility and readability are considered, and also by taking the Royal National Institute of the Blind's (RNB) *Clear Print Guidelines* into account (Macdonald, McMillan, & Kerr, 2010).

3.4.1.4 Roles and responsibilities

Professionals in the current study were reluctant to allocate specific professionals to discuss sexual issues with service-users, and most acknowledged that it could become part of their role in some form, even if building a relationship which enables service-users to feel comfortable about discussing sexual issues. This is perhaps important given that all professionals may be required to handle initial enquiries and dealing with sexually inappropriate behaviour.

However, one participant highlighted a potential problem of this approach using the analogy “everybody’s business is nobody’s business”. ‘Diffusion of responsibility’ is the sociopsychological phenomenon whereby individuals avoid taking on responsibility when their efforts are pooled in pursuit of a shared goal, compared to responsibility on individually assigned tasks (Sweeney, 1973; Ingham, Levinger, Graves & Peckham, 1974; Latane, Williams, and Harkins, 1979). According to Henriksen and Dayton (2006), in the absence of standardised procedures in clinical settings, individual roles and responsibilities are frequently assumed rather than spelled out, meaning that components of care are frequently missed. In contrast, when professionals are made accountable for specific actions, they can begin to monitor and self-manage their own performance (Harkins & Jackson, 1985).

Issues of transference and counter-transference may mean that some professionals feel more uneducated and uncomfortable when dealing with the sexual concerns of the opposite gender. Indeed, being of a different gender has also found to hinder discussion about sexuality in non-TBI settings (Gott et al., 2004; Hinchliff et al., 2004; Humphery & Nazareth, 2001; Price, 2010). This viewpoint is potentially problematic given the high proportion of female (nursing and therapy) professionals in rehabilitation settings, combined with the high predominance of males in the brain injured population (Tagliaferri et al., 2006). This means that sexuality issues are even more likely to go unaddressed. These studies (and the issue discussed here) do however make the assumption that service-users (and professionals) are heterosexual.

3.4.1.5 Dilemmas about risks and vulnerabilities

The virtual explosion of the internet has provided unprecedented opportunity for people with TBI to access information on sexuality issues through websites. In addition, chat rooms may enable people to overcome social and practical barriers to meeting sexual partners. However, with this comes risk. Professionals in the current study raised concerns about service-users being more vulnerable to abuse and exploitation than people in the general population. This theme is significant as it has not previously highlighted by studies investigating professionals' views of discussing sexuality after TBI.

Studies have shown that people with disabilities are more likely to experience abuse than any other group (Ducharme & Gill, 1997; Westcott, 1994). Earle (2001) has suggested that this could be for a number of reasons: Firstly, people with disabilities may rely on others for their care and this dependency creates an environment and opportunity for abuse; secondly (and as suggested by a participant in the current study), potential abusers may perceive people with disabilities as 'easy targets', thirdly, cognitive impairment may mean that some people may find it difficult to articulate the abuse, may be less likely to be believed, and may lack the knowledge required to understand when abuse has taken place.

Related to this, participants also expressed concern that discussing sexual issues with service-users may lead to them engaging in risky or inappropriate behaviours, an assumption which may prevent them from raising such issues. Again this theme is significant as it has not been previously highlighted in studies investigating professionals' views of discussing sexuality after TBI. There are certainly classes of sexual behaviour that would be classified as 'risky', and it is critical for staff to intervene in these cases. For example, Simpson, Blaszczynski and Hodgkinson (1999) found that 6.5% of their sample of TBI participants were identified as having committed some form of sexual offence. However, a criticism of this study is the lack of a non-TBI comparison group. Physiologically, research has indicated that frontal lobe damage can lead

to hypersexuality, sexual disinhibition, and potentially sexual offending (Miller, Cummings, McIntyre, Ebers, & Grode, 1986; Miller, 1994; Sabhesan & Natarajan, 1989). However, it is important to note that participants in the current study did not tend to differentiate between different injury locations, instead referring to persons with TBI as one group.

Compromised frontal lobe functions could also result in some people with TBI not being able to negotiate sex safety because of poor judgement, disinhibition or impulsive behaviours. Only one study has investigated safe sex practices amongst people with TBI (Kramer, Nelson & Li, 1993). The results showed that knowledge about AIDS was variable, with misinformation surrounding the use of condoms. The authors concluded that this is particularly disturbing considering that a high proportion of the sample were engaging in unsafe sexual practices (such as having multiple-sex partners or same-sex partners without using condoms). However, this study is limited as the sample only included participants who also met diagnostic criteria for a substance use disorder. Furthermore, the sample was composed of a small number of non-randomly selected participants, who were all white, and resided in the same TBI rehabilitation facility. Generalisability is therefore limited to a specific sector of the TBI population.

Some professionals raised concerns about placing themselves in a sexually vulnerable position when asking about sexual issues, supporting previous research which has highlighted the concern amongst professionals that service-users may “sexualise” the encounter (Gott et al., 2004; Hinchliff et al., 2004). It is also noteworthy that many involved in the direct care of service-users who have experienced a TBI are female, and service-users tend to be male. Given the close contact that occurs between service-users and professionals, there is the potential for the female staff member to be perceived as a potential sex object” (Davis & Schneider, 1990) (this however makes the assumption that the service-user is heterosexual). According to Davis and Schneider (1990), this could increase the level of discomfort regarding sexuality, especially with less experienced professionals.

Finally, some professionals highlighted that they were worried that they would be disciplined, or face prosecution if they 'crossed boundaries' by talking about sexuality issues. A review of the literature between 1970 and 2006 (Halter, Brown & Stone, 2007) found that firstly, professionals did not feel that they were adequately trained or educated on sexual boundaries issues, and secondly that the available guidelines lacked clarity. This is inadequate given that research has shown that good education is essential to prevent professionals from breaching sexual boundaries (Council for Healthcare Regulatory Excellence [CHRE] 2008a). The CHRE has since produced guidelines and recommendations relating to clear sexual boundaries between professionals and service-users (CHRE, 2008a, 2008b, 2008c), and it is important that professionals are made aware of these. The Sexual Offences Act (2003) may also provide clarification for professionals about unprofessional and unlawful sexual boundaries between professionals and service-users (see also 2.4.2.2 Implications for training).

3.4.1.6 Organisational and structural factors

Professionals felt that the demands that they face within their roles leave them little time to discuss sexuality issues with service-users. This is consistent with previous research from TBI settings (Haboubi & Lincoln, 2003), and also from non-TBI settings (Gott et al., 2004; Guthrie, 1999; Hinchliff et al., 2004; Humphery & Nazareth, 2001; Lewis & Bor, 1994; Stead et al., 2003). It is not known whether the focus on a lack of time is an avoidance strategy. For example, Jarrett and Payne (1995) observed that even during quiet times, nurses were unlikely to engage service-users in one-to-one conversations. Again, this can be understood from a behavioural perspective in that avoidance acts as negative reinforcement by enabling professionals to avoid the discomfort and anxiety associated with raising sexual issues with service-users.

Professionals in Haboubi and Lincoln's (2003) study reported that the service-users' physical wellbeing would act as a barrier to communicating about sexuality. The findings from the current study could be used to explain this viewpoint i.e. a disbelief in the necessity of discussing sexuality with service-

users in the context of their other problems such as ‘walking and talking’ will mean that low priority is attributed to communication about sexual issues. These findings are comparable to those reported by others. For example, sexuality was not considered to be a priority in an acute surgical setting (Guthrie, 1999), in cancer services (Hordern & Street, 2007; Price, 2010; Zeng, Liu, & Loke, 2011), and in an intensive care unit or operating room (Kautz et al., 1990). These claims could be viewed as a means of avoiding the issue, or a representation of the insufficient importance given to the topic of sexuality in the curricula of standard professional education. However, they may well be valid given that the immediacy of physical and physiological treatment in these settings understandably take precedence over a service-users’ psychosocial concerns. Furthermore, these perceptions are indeed likely to be congruent with the service-users’ expectations of the professionals’ role in these acute settings (Magnan et al., 2005; von Essen & Sjoden, 1991).

However, whilst it is understandable that sexual concerns can easily be overlooked in an acute, short hospitalisation stay, they cannot be avoided in the course of a TBI rehabilitation program which often lasts months or in some cases, years. Magnan et al., (2005) have suggested that professionals perceptions that service-users do not expect nurses to discuss sexuality issues may be a way of reducing the cognitive dissonance¹⁵ that comes from how professionals perceive their roles compared to how they actually carry out their roles.

Professionals tended to advocate an indirect approach to dealing with sexuality, believing that addressing other emotional, social and dyadic complaints would resolve any sexuality issues. This is consistent with the findings from Katz and Aloni’s (1999) survey. The authors proposed that this view evolved from professionals not having the adequate tools to manage sexual dysfunction, and therefore they felt that they were doing the best they could under the

¹⁵ Cognitive dissonance is when a person simultaneously holds two cognitions which are psychologically inconsistent – a psychological state of discomfort or tension (Gross, 2005, p. 418).

circumstances, although this was usually unsuccessful in easing sexual problems.

Some professionals highlighted that the clinical environment of the hospital setting means that opportunities for one-to-one time and privacy to discuss sexual issues with service-users is scarce. This supports findings from the literature (Stead et al., 2003). Participants in one focus group also highlighted that due to the hospital environment, service-users and their partners do not have the opportunity to 'test out' whether there are any sexual difficulties. Indeed, previous research has found that the need for intimate interaction between service-users and their partners often goes unrecognised, with opportunities often denied (Blackerby, 1990; McCann, 2010b; Price, 2010).

3.4.2 A MODEL OF INTENTION TO DISCUSS SEXUALITY

The Theory of Planned Behaviour (TPB) (Ajzen, 1991) provides a useful framework for understanding the findings from the current study (figure 6). The model makes two propositions: First, the best predictor and proximate antecedent of behaviour is intention, which comprises the cognitive, motivational and affective internal processes associated with a person's readiness to perform a given behaviour. Second, attitudes, norms and perceived behavioural control are seen as simultaneous determinants of intention.

Attitudes relate to the degree to which a person has a favourable or unfavourable appraisal of the behaviour in question. Professionals' beliefs about the importance and relevance of discussing sexuality, alongside the perceived costs and benefits of discussing it, will affect their decisions of whether to do so. For example, the belief that discussing sexual issues with service-users may lead to them to engage in risky or inappropriate behaviours will reduce professionals' intention to address it.

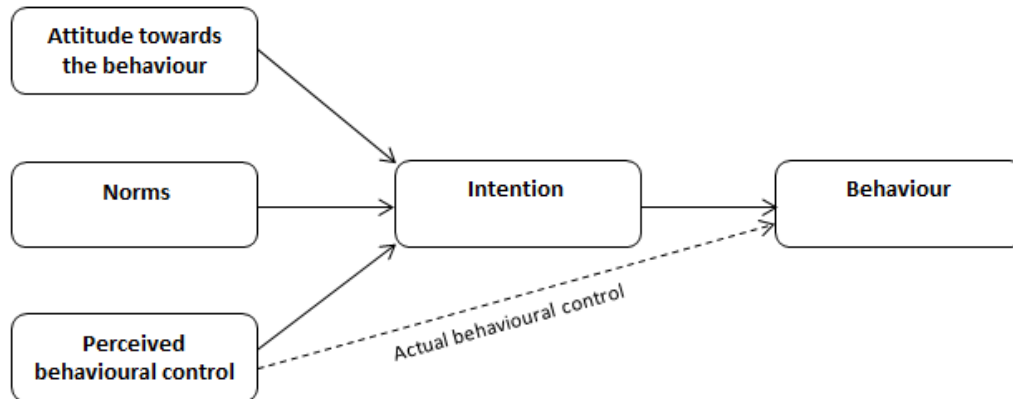


Figure 6. The theory of planned behaviour (adapted from Ajzen, 1991).

Norms are concerned with the impact of subjective social influence, as well as the objective behaviour of relevant others. Some professionals believed that they will be judged negatively for discussing sexuality (either by other professionals or by service-users themselves), which will weaken the intention to raise it.

Finally, perceived behavioural control describes the self-assessment of capacity, skill, and the opportunity to perform the behaviour in question. Professionals' perceived lack of knowledge, skills and training, combined with organisational barriers such as a lack of time, resources and privacy will also affect overall intention to raise sexual issues. This is similar to Bandura's (1977; 1982) concept of self-efficacy (as discussed earlier). As seen in figure 6, actual behavioural control (i.e. the *actual* capacity, skill, and opportunity) moderates the impact of intentions on behaviour.

3.4.3 IMPLICATIONS FOR CLINICAL PRACTICE, TRAINING AND POLICY

The World Health Organisation considers sexuality to be a central aspect of being human (World Health Organization, 2012). It therefore seems logical to suggest that a holistic approach to rehabilitation would include sexuality. Furthermore, the National Sexual Health Strategy (Department of Health, 2001),

and the *Rehabilitation from ABI: national clinical guidelines* (RCP & BSRM, 2003) have included the drive for more attention to be paid to the assessment of sexual and relationship needs, and both were explicit about the services and treatments that people could expect to receive. Based on the results of the current study, recommendations on how this can be achieved are given below.

3.4.3.1 Implications for clinical practice

Firstly, it is recommended that a more proactive approach to addressing sexuality is taken. Of course (and to reiterate the concerns of some participants), consideration must be given to the timing of treatment implementation, particularly given that service-users and their families may be preoccupied with more immediate concerns and are not able or ready to consider sexuality in the spectrum of their disability, rehabilitation goals, or long-term functioning (Blackerby, 1990). Indeed, sexual problems may only manifest when individuals resume sexual activities, which in some cases may be months after their initial injury. However, it is important that professionals acknowledge that sexual issues may develop at some point. This opens the door so that treatment can be initiated at a later stage.

Several models have been developed which may help to provide professionals with a structure with which to address sexual issues. The PLISSIT model (Annon, 1976), and BETTER model (Mick, Hughes, & Cohen, 2004) are the most commonly described within the recent literature (Cort, Attenborough, & Watson, 2001; Hordern, 2008; McInnes, 2003; Quinn & Happell, 2012). The PLISSIT model has been chosen for discussion because it offers a useful framework with which to discuss sexuality. The PLISSIT model has also become widely adopted by organisations such as the Royal College of Nursing (RCN) and the British Association of Sex and Relationship Therapists (BASRT).

The acronym PLISSIT represents the four levels of intervention (see table 5), which range from the simplest interventions to more complex, requiring a higher level of expertise and most likely postgraduate qualifications (McInnes, 2003). According to Annon (1976), most sexual problems can be resolved if people are

given permission to be sexual, to discuss sexuality and if they receive information about how to address sexual problems, with few people needing intensive therapy. All levels are underpinned by giving permission (Davis & Taylor, 2006). This may initially involve letting service-users know that it is okay to be concerned about sexual issues, and responding to service-users' sexual concerns in a warm, empathic manner that demonstrates a comfort in addressing sexuality issues (Ducharme & Gill, 1990). Thinking about sexuality conversations in a different way i.e. as a support for the emotional wellbeing for the service-user, may help professionals to move away from the discourse that sexuality is a 'specialist' issue which requires expert knowledge, skills and training. Indeed, one participant in the current study reflected on how sometimes service-users may just want to list their problems, "knowing that there's not always an answer".

The model allows staff to rate their own competence and to determine the level of intervention with which they feel most comfortable (Ducharme, 2000). At any of the stages, as professionals reach their limits in terms of their own level of comfort and competency, appropriate referrals should be made. This is relevant in the context of the current study where professionals acknowledged feeling more competent in some areas as opposed to others (for example, 'mechanical' versus 'emotional' issues).

Table 5. The PLISSIT model (adapted from Annon, 1976)

| Level of intervention | Description |
|------------------------------|--|
| Permission | Giving permission to be sexual, and normalising sexual desire. For example, “many people with TBI have concerns about sexuality. Is there anything you would like to talk about or to ask?” |
| Limited Information | Providing relevant information about sexual matters. The information that is provided needs to be inclusive and not restricted to assumptions made about the service-user or their sexual preferences. |
| Specific Suggestions | Giving suggestions about ways to address sexual problems. This requires more knowledge than providing limited information. |
| Intensive Therapy | Making referrals for specialist interventions. This may include sex therapy, more general psychological therapy (such as that provided by clinical psychologists or psychotherapists), urology, genitourinary medicine, gynecology, or continence specialists. |

It is therefore important that agencies identify those areas that are outside of the scope of practice or expertise, and develop links to specialist sexual health or therapy services to address these needs. Indeed, *The Rehabilitation following ABI: national clinical guidelines* (RCP & BSRM, 2003) state that health and social services managers should work in partnership to ensure that an adequate range of services exists to meet the specific needs of those affected by brain injury. Amongst others, the guidelines make specific reference to sexual and relationship counselling services. This is particularly important in the context of the current study as professionals highlighted concerns about opening up the ‘can of worms’ of sexual issues when they are unaware where to refer service-users on to. It may be useful for rehabilitation services to bring in external

agencies to talk to service-users about sexual issues, for example, disability educators from Family Planning Association could provide information about safe-sex practices (Simpson, 2001).

Finally, it is important to note the limitations of the PLISSIT model. Firstly, van Loon, Koch, and Kralik (2004) have suggested that people who have a history of sexual abuse would not engage in communication using this model. Secondly, it could be argued that the linear process lacks the more natural, interactive nature of talk, as well as aspects of reflection and reviewing clinical practice. Davis and Taylor (2006) have developed a new, circular version of the PLISSIT model (The Extended-PLISSIT or Ex-PLISSIT model) in light of these criticisms. Finally, Dune (2012) has argued that the model may problematise and pathologise variations in human sexual experience, embedded in a framework where a satisfying sexual life must be performance-based. As Whipple and McGreer (1997) point out, it is important for professionals to “be aware that there is no right or normal way to have a sexual experience. Each person is unique and responds differently depending on many variables” (p. 516).

2.4.3.2 Implications for training

It is essential that training of professionals is enhanced in order to increase knowledge, skills, and comfort level in approaching sexuality issues post-TBI (Gill, Sande, Robins, Mazzei, & Struchen, 2011), and indeed professionals in the current study highlighted training as a potential facilitating factor. Attempts have been made to provide training on sexuality, however, this usually requires professionals to be aware of sexual issues, and have sufficient interest to actively seek out the training. It is therefore recommended that a more proactive approach to training is taken, by providing more detailed teaching at undergraduate stages and during vocational training (including nursing, occupational therapy, physiotherapy and clinical psychology training courses). This supports Foucault’s (1979) desire for sexuality to be incorporated more fully into the mainstream, and is one step towards normalising sexuality as just another aspect of an individual’s life.

Firstly, and as mentioned above, the PLISSIT model may provide professionals with a structure with which to address sexual issues. Indeed, training professionals in the PLISSIT model has been shown to increase staff knowledge, comfort and skill in managing sexual issues (Fronek, Booth, Kendall, Miller, & Geraghty, 2005; Tepper, 1997), all of which were raised as barriers by the participants in the current study. It is also important for professionals to develop a common, up-to-date understanding of the sexual issues that can arise post-TBI. This would enable professionals to effectively communicate information to service-users and their families, provide a basis for intervention techniques, and may also prevent misunderstanding of service-users' behaviours (Blackerby, 1990).

Professionals in the current study reflected on the difficulties of managing hypersexuality and disinhibition. This indicates that professionals may benefit from an overview of behavioural modification techniques, with an emphasis on the importance of limit-setting, consistent and direct feedback, and professional boundaries (Ducharme, 2000). It is important that professionals target reduction of inappropriate behaviours, as opposed to the sexual drive underlying them, and that this is conveyed to service-users. Given one participant's comment that inappropriate behaviour is discussed but not *appropriate* behaviour, it is also advisable that specific alternative behaviours are suggested to service-users.

Clinical psychologists and neuropsychologists could potentially have an important role in facilitating training, and it is therefore important that they are competent in the psychological and psychosocial aspects of sexuality, as well as the neurobiological underpinnings of sexual dysfunction and sexuality (DenBoer & Hough, 2010).

As mentioned above, some service-users experiencing difficulties in sexuality and intimacy may need input from specialist services. Professionals will likely benefit from increased awareness of the local services that service-users can be referred to, as well as increased knowledge about appropriate referrals to these services. This may include service-users with complex sexual

dysfunctions, difficult relationships, psychiatric histories or severe behavioural problems (Ducharme & Gill, 1990), although referral criteria are of course set at an organisational level.

Perhaps most importantly, training should be used to enable professionals to develop comfort and confidence in dealing with sexuality issues, as this is a known moderating variable which impacts on willingness to discuss sexual issues. To increase comfort, it is important that professionals have the opportunity to explore their feelings and emotions about sexuality in a safe, supportive environment (Akinci, Yildiz, & Zengin, 2011). This could take the form of a workshop, for example, (although not currently available in the UK), the Sexual Attitude Reassessment workshop (SAR) is a structured group experience to promote professionals' awareness of their attitudes and values related to sexuality, and to assist them in understanding how these will affect them professionally and personally. Other ways to overcome personal barriers about sexuality could take place in the form of in-service reflective practice groups or through regular supervision, which clinical psychologists and neuropsychologists may have an important role in facilitating. Indeed, professionals in the current study highlighted supervision as a facilitating factor in communicating about sexuality issues.

It is also important that professionals are encouraged to make time to practice discussing sexuality with service-users, "since confidence develops with mastery and mastery develops with practice" (Akinci et al., 2011, p. 18). As pointed out by one participant, the use of role plays to practice talking about sexuality could potentially be beneficial. Some professionals may also benefit from training in basic counselling techniques, such as effective listening skills, validating the service-user's experience, supporting any feelings of loss, being empathic to the degree to difficulty involved in the disclosure, and willingness to suspend judgment (Ducharme, 2000; Ducharme & Gill, 1990). Professionals concerns about "scaring off" service-users indicates that they may benefit from input to understand the factors associated with ruptures of the therapeutic alliance and ideas about how they could attempt to repair this. Again clinical psychologists could fulfil this role.

Finally, professionals raised concerns about the risks involved with service-users engaging in sexual relationships, as well as concerns about breaching sexual boundaries by discussing sexuality issues. Certainly, understanding of the law is an important matter and should be considered an essential part of the healthcare curriculum. The Sexual Offences Act (2003) has recently been introduced and this has clarified many legal issues in relation to people with disabilities. Furthermore, the CHRE (2008a) have produced detailed guidelines and recommendations for higher education institutes, students, regulators, Royal Colleges, and the Department of Health on how training on sexual boundaries can be designed and implemented. It is recommended that both of these are included in any training.

3.4.3.3 Implications for policy

This study also has several implications for policy-makers, as without clear direction from the professionals' organisation, there is the potential for individual professionals to contravene (either overtly or more passively) components from training that they do not agree with or accept (Blackerby, 1990). Direction for professionals is also important given the complex array of ethical, legal, personal and professional dilemmas that can arise when considering how to address and manage sexual issues post-TBI. The continuum of 'facilitated sex' represents an array of needs and activities from the provision of accessible sexual information and advice, to the organisation of sexual surrogacy (Earle, 2001), and it is not suggested that professionals should play a role in all of these. Importantly, sexual surrogacy is not widely available in the UK, as it is in some countries such as Denmark and in some parts of the United States of America (USA) (Shakespeare, 1998). However, dilemmas can arise at all aspects of the continuum; for example, as pointed out by one participant, some professionals may not see any harm in a service-user accessing pornography, whilst others may find it morally reprehensible and dehumanising.

The development of policy should therefore include a consideration of the following: What role should professionals play in enabling social interaction, for example visiting a nightclub? What role should staff play in purchasing pornographic magazines? What role should they play in enabling clients in the community access sex workers? Should they provide information on how to arrange this, or assist in arranging suitable transportation? It is recognised that as well as obvious practical challenges, these questions also present moral and legal challenges to services, and may potentially place facilities in high-risk situations (Davis & Schneider, 1990). Policies should also be aimed at the prevention of inappropriate, harmful (both psychologically and physically) and dangerous behaviours, such as public masturbation, sexual assault of staff, other service-users and members of the general public, or sexual behaviour that may lead to unintended pregnancies and the contraction of sexually transmitted infections (STIs).

Sexuality policy and procedures can either constitute a stand-alone document, be written up as a manual (e.g. Medlar, 1998), or be incorporated within the broader policy and procedure framework of the organisation. In any case it is important that policies are consistent with government legislation, and are conveyed to professionals in a timely manner to provide direction regarding overall philosophy.

Whilst these guidelines for clinical practice, training, and the development of policy seem like a step closer to the incorporation of sexuality into a holistic approach, the responsibility for implementing these remains on the individual professionals and rehabilitation organisation. The cost of TBI rehabilitation and treatment continues to increase, and it can be assumed that the implementation and administration of these guidelines would be both time consuming and resource intensive. This leads to the significant dilemma: Who will pay?

3.4.4 IMPLICATIONS FOR FUTURE RESEARCH

This section discusses future research directions stemming from the findings. Those already identified in the journal article are expanded upon (points 1 to 3), and other possible directions are discussed (points 4 to 6):

1. Professionals made a number of assumptions about service-users' expectations of communication about sexuality, including the belief that service-users do not expect them to raise sexual issues, and the belief that service-users do not consider sexuality to be a priority due to other, more pressing concerns. There was also an assumption that because service-users do not raise sexual issues, they must not want to discuss it. Further research is therefore needed to determine whether these assumptions match the reality of service-users expectations, which could be achieved through recruitment of service-users who have experienced a TBI and their partners. Participants in the current study commented that they would be interested in hearing service-users' opinions about sexual issues and queried whether the researcher was planning to collect data on this (indeed, an initial research aim had been to compare the perceptions of professionals and service-users – see 2.4.6 Critical reflection). Efforts should be made to recruit service-users of varying relationship status, non-heterosexual service-users and from an ethnic and cultural mix that is broadly representative of people with TBI in the UK;
2. The following themes have not been previously highlighted in the rehabilitation literature, and therefore these warrant further attention:
 - a. Professionals placed high value on '*Teamwork, consultation and supervision*' when considering how to overcome their lack of knowledge, skills and expertise in dealing with sexual issues;
 - b. When discussing ways to overcome anxiety about discussing sexual issues, some professionals advocated a more exposure-based approach as opposed to training for professionals;

- c. The subtheme of '*Sexuality is not included on outcome measures*' includes the viewpoint that professionals feel less obliged to address sexual issues because there are no consequences for not addressing it. This could potentially have important implications for which issues professionals and organisations choose to address in rehabilitation settings.

Further exploration of these themes may include investigating whether professionals in other settings and geographical locations share these views, and if so, the perceived impact on their role;

3. Investigation into the clinical applications of this research is certainly called for. Training programs should be evaluated to investigate the impact on professionals' knowledge, comfort, confidence and willingness to discuss sexuality with service-users who have experienced a TBI. Professionals from varying demographic and professional backgrounds and from different disciplines should be recruited to ensure that the training is appropriate and applicable to a wide population;
4. Participants in one focus group reported that service-users tend to leave the question pertaining to sexuality blank on a routine assessment questionnaire. Firstly, it is not known whether this finding is unique to this particular setting, so further research should therefore be conducted in other TBI settings. Secondly, a number of hypotheses were generated by professionals relating to why this might be the case, but further research is recommended to investigate service-users' perceptions of the use of questionnaire measures to communicate about changes to sexuality;
5. There is also a lack of research into professionals' experiences and perceptions of communicating with service-users about sexual issues from a social constructionist perspective. Discourse analytical work for example could build on the current study by examining professionals' constructed accounts of sexuality and of working with sexuality issues;
6. When reviewing the literature about sexual changes that occur after TBI, the focus is on the negative aspects. Future research could

consider adopting a 'positive psychology' approach which considers peoples' strengths and resilience. For instance, future research could consider the ways in which people with TBI adapt to sexual difficulties and continue to enjoy fulfilling relationships. Further research could also focus on the positive experiences of sexuality being addressed in rehabilitation, in order to identify and share good practice.

3.4.5 STRENGTHS AND LIMITATIONS OF THE RESEARCH

One of the key strengths of the study was the qualitative method used to gather and analyse the data. Indeed, this study is the first UK study to specifically explore professionals' subjective perceptions and experiences of communicating about sexuality after TBI. TA was considered ideal because it allowed an in-depth analysis of professionals' perceptions and experiences, hence enriching the picture obtained through previous quantitative studies. The inductive, semantic approach also enabled the researcher to remain 'close' to the data, and best represent professionals' views. Furthermore, a number of quality assurance measures were put in place to improve the trustworthiness of the findings.

However, a number of limitations must be considered. Firstly, this study consisted of a small and homogenous sample of 24 participants from the one region of the UK. It therefore cannot be assumed that the themes identified are representative of the views of professionals in other teams, without further research being conducted. A larger, more geographically diverse sample would ensure greater representativeness of findings, although that said, generalisability may still be limited. Secondly, and importantly, representativeness and generalisability was not the primary aim of this study, or indeed the aim of many qualitative studies.

Purposive sampling was employed to select professionals which fit the aims of the study. However, it is acknowledged that this may have created sampling bias given that the professionals who volunteered may have had an interest in

sexual issues, and/or were motivated to increase their awareness. A focus group methodology was chosen to help professionals to volunteer to take part in a non-threatening environment, although the views of professionals who were unwilling to volunteer for participation may need accessing. Means need to be found to sensitively encourage those who were less likely to volunteer to partake in research, for example, by offering potential participants the choice of whether to attend a focus group or individual interviews (Lambert & Loisel, 2008). However, it is acknowledged that this population would still be difficult to access.

The focus group methodology has the additional advantage of observing participants in action, and also allowed access to the participants' own language. Focus groups also allowed for a more elaborated account through the analysis of group interaction data, such as participants supporting and challenging each-others' views. Whilst a number of authors have suggested that the context of focus groups enhance openness and disclosure (e.g., Kitzinger, 1995; Wilkinson, 1998), it is important to consider the possibility that the opposite may have occurred, both in what participants do say and what they do not (Hollander, 2004). Firstly, the researcher cannot be sure whether or not a general social desirability bias influenced the data (Hollander, 2004), and secondly, participants may have 'censored' opinions or experiences that differed from the 'majority view' of the group (Sim, 1998). The fact that in the context of the current study, participants must continue to work together after their participation is complete could have made inhibition even more likely. As such, this may have influenced the findings: Themes may only reflect the dominant ideas in each group, whilst alternative discourses could have been silenced. Triangulating the focus groups with individual interviews may have enabled access to any alternative views, and may have provided deeper insight into understanding the research question (Lambert & Loisel, 2008).

3.4.6 CRITICAL REFLECTION

This section critically discusses some of the wider issues raised by this research study. The discussion is organised as a temporal account around

themes derived from the researcher's reflective research diary (extracts are presented in *italics*). Throughout this section, the main difficulties faced during the development and data collection phases of the study are outlined.

3.4.6.1 Conceptualising the research

The rationale for undertaking this study came from my own previous experience of working in TBI settings: I began to reflect on the possible reasons why sexuality was infrequently discussed. The project was originally designed to include both professional and service-users as participants, but obtaining ethical approval to include service-users was challenging due to the sensitive nature of the topic. I found the feedback from the Research Ethics Committee (REC) incredibly disappointing. Following discussion with my research supervisor and others, it was decided to change the study to include professionals only. It was felt that this would be sufficient for the study given that only one qualitative study has been conducted with professionals in TBI settings (Katz & Aloni, 1999), and given that this study is limited for a number of reasons.

The next stage was to speak with professionals about the feasibility of conducting research in this area. *Generally, the idea has been met with positivity and enthusiasm, with professionals agreeing that this is an understudied area and that further exploration would be a useful addition to the literature. One professional felt that I might encounter difficulties in recruitment given the sensitive nature of the topic. I am also aware that professionals are incredibly overworked, and given budget cuts and increasing demand for their services, will they have time to take part? However, I have to remember that the emphasis of qualitative research is not on recruiting large samples to produce objective generalisable findings, but in-depth subjective accounts.*

3.4.6.2 A number of decisions

The following weeks and months were categorised by many decisions. *Individual interviews would certainly be appropriate, however, I am keen to use focus groups for a number of reasons, including the potential benefits of capturing the sociocultural and organisational context of the professionals' accounts.*

It will be important to recruit professionals from both inpatient rehabilitation and community settings, given that these professionals constitute the 'first line' of healthcare provision post-TBI. Professionals working in accident and emergency, intensive-care, and neurosurgical settings will be excluded as they are likely to be involved in the early management of TBI only (National Institute for Health and Clinical Excellence [NICE], 2007). It was also felt that it would be useful to recruit some non-NHS participants, as well as professionals from a range of professional backgrounds, to increase the heterogeneity of the sample.

Reflecting on my epistemological stance identifies a position of critical realism. Given that I am interested in exploring professionals' perceptions and experiences of communicating about sexual issues, I need to select a method that allows full exploration of this. TA has been subject to much criticism in the past, relating to the lack of clarity and limited interpretative power (Braun & Clarke, 2006), however, when comparing it to other methods of analyses I feel that it will be useful for addressing my research aim. Group interactions have been described as an underused and underreported source of data in focus group research, with focus group data often presented as if they were one-to-one interview data (Wilkinson, 1998). I find this surprising given that group interaction is the most distinctive feature of the method, and I am keen to incorporate the 'group effect' into my TA.

3.4.6.3 Ethics and R&D

Applying for ethical approval has undoubtedly been one of the most challenging parts of the research process. I became frustrated as I learned that each R&D department operates very differently, and there have been numerous delays as R&D departments requested additional paperwork to be provided and signed by different people. I realise that I underestimated the time taken to obtain ethical approval; something which I will bear in mind when conducting research in the future.

3.4.6.4 Planning the focus groups

I have just booked in my first focus group! In preparation for this, I have been reading articles on focus group moderation. One quote by Agar and MacDonald

(1995) struck me in particular; “with a method that featured group interactions, we thought the moderator should keep his nose out of it whenever possible” (p. 81). Indeed, given my aim to observe the groups’ natural communication, I consider it important to minimise my controlling role. I therefore aim to use a less directive style of moderating, which I think will be important to state at the beginning of each focus group.

I have also started to wonder about how my questions will be received: Will professionals perceive that I am criticising their current practice? When introducing myself to participants, it might be worth reflecting that the initial idea for the project originated from my personal experience of not addressing sexuality issues with service-users who have had a TBI. This should hopefully help to build rapport with participants by indicating to them that I understand their experiences, reduce power imbalances, and may also encourage participants to be more open. However, I cannot avoid the fact that to the teams I am researching, I am an ‘outsider’ (Warr, 2005), and this will influence the data collected, as well as my analysis.

I encountered a number of complications relating to the logistics of setting up the focus groups. Assembling the focus groups was challenging due to professionals’ busy diaries. This meant booking focus groups up to two months in advance of them taking place, essentially delaying the data collection stage. I arrived at one focus group to find that only two participants had turned up due to the others having other commitments. I therefore made the decision to cancel the focus group and rearrange it for another time. Focus groups have been reported to be a quick and efficient way of obtaining data (Morgan, 1988), yet this does not seem to take into account the large amount of preparation required and potential for unpredictable complications.

3.4.6.5 After the focus groups

I have just finished my last focus group. I have noticed that over time, I have become more comfortable with the low-moderator style. Taking a back seat has also enabled me to stay close to the focus group schedule, compared to in the first focus group where I noticed that I was straying by asking ‘filler’ questions.

Overall, I think that the focus groups functioned better than I anticipated: Participants asked questions of each other, and challenged each other's ideas.

In all focus groups, two or three group members tended to dominate the discussion. *Some participants spoke very minimally, and when they did, their voices were so quiet that the recorder struggled to pick up what they were saying: "Who are these silent voices in the group? Why aren't they talking? What do they have to say?"* (Agar & MacDonald, 1995, p. 83). I was initially worried about this, wondering if I should have done more to encourage the voice of the 'quiet and shy' (Bradbury-Jones, Sambrook, & Irvine, 2009). However, upon reflection I have realised that this gave me useful insight into the dynamics of the staff teams. Professionals may have chosen to remain quiet for a number of reasons, including 'social loafing' i.e. when people don't put in as much effort when part of a group (Asbury, 1995), or because the less experienced members felt uncomfortable expressing opinions in the company of others that they perceived as more powerful, knowledgeable or experienced than themselves. It was important to be mindful of these dynamics when interpreting the findings.

3.4.6.6 Transcription

My observation that some participants were noticeably quieter than others led me to reflect on the importance of incorporating non-verbal gestures and (less salient) verbal utterances into the transcripts. Initially I had considered using an external transcription service, however I realised that the transcriber would lack such contextual knowledge. I therefore made the decision to transcribe all of the recordings myself.

I came into the research expecting transcription to be a chore, but I have found it hugely helpful to my later analysis: Braun and Clarke (2006) have stated that immersion within the data is an important first stage. Furthermore, as I was transcribing, I found myself reading the transcripts in the voice of the participant, and I think that this helped me remain grounded in the data rather than my own interpretation.

3.4.6.7 Analysis stage

I have chosen to undertake an inductive, semantic analysis to ensure that my analysis stays firmly grounded in the data and captures the whole dataset. However, in line with my critical realist position, I am aware that no research is conducted in a vacuum. I have come to the analysis with knowledge of the existing literature, and this will undoubtedly lead me to focus on certain aspects of the data at the expense of others.

In an attempt to minimise bias, the transcripts were coded independently by my research supervisor. The discussions which followed were incredibly helpful, enabling me to consider other possible competing interpretations and explanations of the data. This involved both of us playing “devil’s advocate” at times (Barbour, 2001). Even so, I do not think that research can be completely free of bias and I did not strive to achieve this.

3.4.6.8 Writing up

I saw writing the results and discussion as yet another part of the analysis process. Due to the large amount of data, numerous decisions were made regarding which data to include and which data to leave out. I felt a sense of wanting to do justice to all the participants’ contributions, and given space constraints, I initially found myself side-lining the group interaction data. Once aware of this, I made a conscious effort to include it. Although attempts were made to justify decisions of what to include through an audit trail, I am aware that I have inevitably had an important influence over which data to present.

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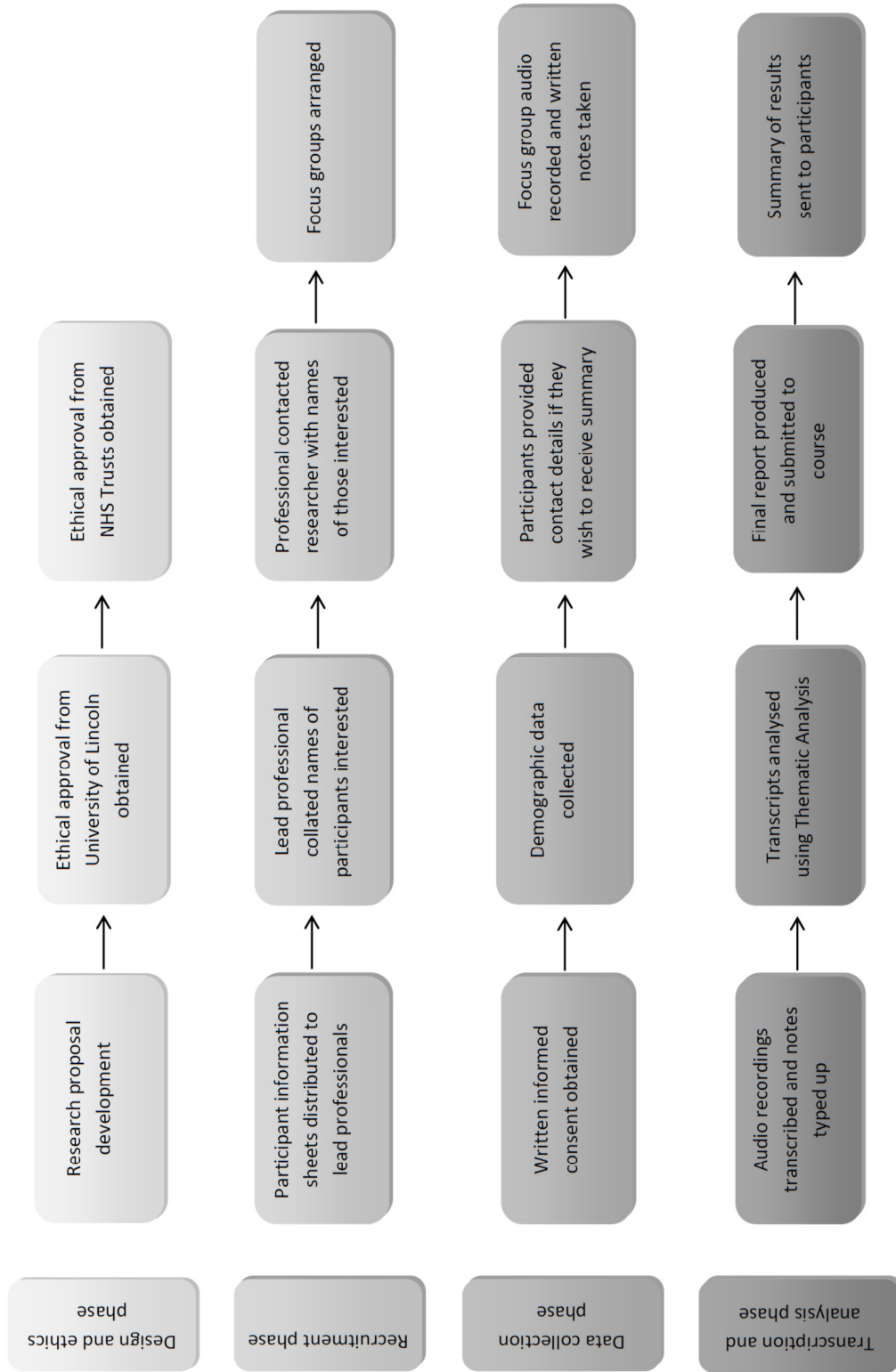
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Appendices

Appendix A: Research procedure



Appendix B: Focus group schedule

- **What are your experiences of discussing sexuality with service users after TBI?**
- **Do you think professionals should discuss sexual issues with service users?**
 - Which professional do you think should be responsible for discussing sexuality with clients? (E.g. nurses, occupational therapists, GP, psychologists, other)
 - What are the advantages and disadvantages of discussing sex with clients?
- **What do you think the barriers are to professionals having discussions about sexual issues after TBI?**
 - What concerns might professionals have about discussing it?
 - What do you think professionals/service-users are afraid of?
 - What impact does this have on service-users?
- **How do you think these barriers could be overcome?**
 - Do you think this should/could be changed?
 - If so, how? What can be done to encourage or facilitate discussions?
 - What would professionals and service-users need to help begin talking about these things?
- **Is there anything else you would like to discuss?**

Appendix C: Demographics of focus group participants

Table 6. Age distribution of participants (n=24)

| • Age bracket | • Number of participants (percentage) |
|---------------|---------------------------------------|
| • 18-24 | • 7 (29.2%) |
| • 25-34 | • 7 (29.2%) |
| • 35-44 | • 4 (16.7%) |
| • 45+ | • 6 (25%) |

Table 7. Job roles of participants (n=24)

| • Job role | • Number of participants (percentage) |
|----------------------------|---------------------------------------|
| • Occupational therapists | • 6 (25%) |
| • Support workers | • 5 (20.8%) |
| • Therapists (other) | • 5 (20.8%) |
| • Psychological therapists | • 3 (12.5%) |
| • Case managers | • 2 (8.3%) |
| • Physiotherapists | • 2 (8.3%) |
| • Medical Doctors | • 1 (4.2%) |

Table 8. Gender of participants (n=24)

| • Gender | • Number of participants (percentage) |
|----------|---------------------------------------|
| • Female | • 18 (75%) |
| • Male | • 6 (25%) |

Table 9. Experience of participants of working with clients (n=24)

| • Time working with clients (years) | • Number of participants (percentage) |
|--|--|
| • < 1 | • 1 (4.2%) |
| • 1-5 | • 8 (33.3%) |
| • 5-10 | • 7 (29.2%) |
| • 10-20 | • 2 (8.3%) |
| • 20+ | • 6 (25%) |

Table 10. Experience participants of working with clients with TBI (n=24)

| • Time working with clients with TBI (years) | • Number of participants (percentage) |
|---|--|
| • < 1 | • 2 (8.3%) |
| • 1-5 | • 11 (45.8%) |
| • 5-10 | • 4 (16,7%) |
| • 10-20 | • 5 (20.5%) |
| • 20+ | • 2 (8.3%) |

Appendix D: Transcript conventions

| | |
|-------------------------|---|
| (.) | Indicates an accountable pause |
| - | Indicates person stopped in mid-sentence. |
| [words [more words | Indicates the start of overlapping speech with the utterances in square bracket above or below |
| {place/name etc} | Indicates information that has been removed to preserve anonymity |
| <i>(laughs)</i> | Indicates laughter |
| <i>Words in italics</i> | Indicate speaker was talking whilst laughing |
| <u>Words underlined</u> | Indicates speaker emphasised these words |
| ((double brackets)) | Indicates additional researcher's comments, where this is important for the interpretation of the utterance. For example, information about tone of voice, body movements, who a remark was directed at, facial expression etc. |

Appendix E: Ethical approval documents



Lincoln, 2-11-2011

Dear Kerry Dyer,

The Ethics Committee of the School of Psychology would like to inform you that your project on "comparing and contrasting health professionals' and service users' perceptions of having discussions about sexuality following Traumatic Brain Injury" is:

- approved
- approved subject to the following condition:
- invited for resubmission, taking into account the following issues:
- is rejected. An appeal can be made to the Faculty Ethics Committee against this decision (cawalker@lincoln.ac.uk).
- is referred to the Faculty Ethics Committee. You will automatically be contacted by the chair of the Faculty Ethics Committee about further procedures.

Yours sincerely,



Emile van der Zee, PhD

Chair of the Ethics Committee
School of Psychology
University of Lincoln
Brayford Campus
Lincoln LN6 7TS
United Kingdom
telephone: +44 (0)1522 886140
fax: +44 (0)1522 886026
e-mail: evanderzee@lincoln.ac.uk
<http://www.lincoln.ac.uk/psychology/staff/683.asp>

From: Emile van der Zee
Sent: Sun 08/01/2012 17:22
To: Kerry Dyer (10197317)
Subject: Re: Ethics application

Hi Kerry, no worries, if you only do a subset of what you originally said you would do it does not affect your ethics approval, all my best,

Emile

Sent from my iPad

On 8 Jan 2012, at 17:20, "Kerry Dyer (10197317)" <10197317@students.lincoln.ac.uk> wrote:

Hi Emile,

Following my REC panel I have decided to change my study to only include staff (as opposed to staff and patients). I am wondering how this effects the ethical approval I have already gained from the university. i.e. whether I need to re-apply for approval or whether to send you my amended information sheets etc?

Many thanks and best wishes,

Kerry

ISSUED
28 MAY 2012



Research and Development Office

TRUST APPROVAL LETTER

Ms Kerry Dyer
Trainee Clinical Psychologist
Trent Doctorate in Clinical Psychology
1st Floor, Bridge House,
Brayford Pool
Lincoln
LN6 7TS

Dear Ms Dyer

Re: Discussing sexuality after traumatic brain injury: perceptions of health professionals.

Ref. [REDACTED]/2012/005

I am pleased to confirm Trust management approval for you to proceed in accordance with the agreed protocol, the Trust's financial procedures for research & development and the Research Governance Framework (which includes the Data Protection Act 1998 and the Health & Safety at Work Act 1974).

Please supply the following to [REDACTED]

- the actual start and end dates of this study (**before the study commences**).
- details of any publications arising from this research project.
- a final report and a report every six months if the study duration is greater than six months.
- notification of any adverse event or changes to the protocol or if the trial is abandoned.

Please note that approval for this study is dependent on full compliance with all of the above conditions.

This project did not require ethical review by a Research Ethics Committee under the UK Health Departments' Governance Arrangements for Research Ethics Committees (GAFREC) in accordance with NRES algorithm dated August 2011.

I would like to take this opportunity to wish you every success with this study.

Yours sincerely,

[REDACTED]

[REDACTED]

RESEARCH & DEVELOPMENT OFFICE



28th May 2012

Study Title: Discussing sexuality after traumatic brain injury: Perceptions of health professionals
R&D Ref: [REDACTED] 2012/005

In accordance with your application and subsequent R & D approval dated 28th May 2012, the following documentation was reviewed and may therefore be used on the above study with Trust approval.

- Research Proposal v2 dated 08.01.12
- Participant Information Sheet v4 dated 09.05.12
- Participant Consent Form v4 dated 09.05.12
- Focus Group Schedule v1 dated 09.11.11



Ms Kerry Dyer
Doctorate in Clinical Psychology
Health, Life & Social Sciences
Brayford Pool
Lincoln University
Lincoln
LN6 7TS

Dear Ms Kerry Dyer
Re: 12CP001

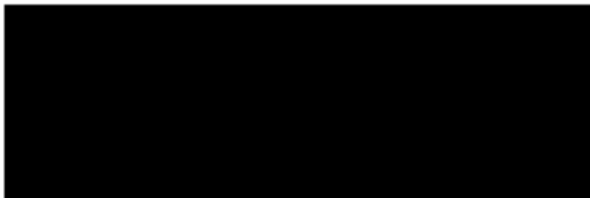
Discussing Sexuality after Traumatic Brain Injury

Thank you for your letter y informing R&I of the following amendments:

- To recruit 5-8 staff members from [redacted] to take part in a 60-90 minute focus group, separate to the [redacted] and providing information sheet.
- Email from Kerry Dyer dated 10/04/12 stating clinical lead authorization in principle from [redacted]

R&I approval of the amendment is subject to the NUH header and relevant contact details being added to the study paper work where appropriate.

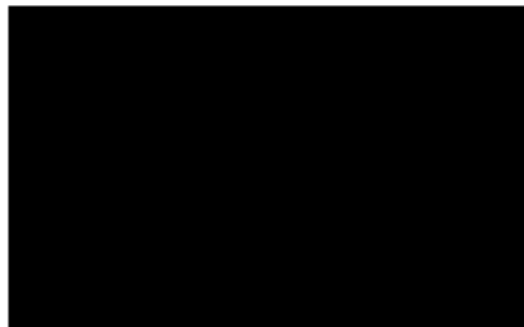
The amendment has been given R&I approval, however you may be contacted in due course if we wish to re-visit the original costings attached to the study.





NHS

 research &
innovation



29 MAR 2012

Ms Kerry Dyer
DOCTORATE IN CLINICAL PSYCHOLOGY
Health, Life & Social Sciences
Brayford Pool
Lincoln University
Lincoln
LN6 7TS

Dear Ms Kerry Dyer

Re: 12CP001

Discussing Sexuality after Traumatic Brain Injury

The R&I Department has considered the following documents:

IRAS NHS R&D form version 3.4
IRAS NHS SSI form version 2.1
Participant information sheet version 3 dated 09/11/11
Participant consent form version 3 dated 09/11/11
Focus Group schedule version 1 dated 09/11/11
Protocol version 2 dated 08/01/12

Your study now has R&I approval, on the understanding and provision that you will follow the conditions set out below.

Conditions of Approval

That you:

1. Comply with all relevant laws, regulations and codes of practice applicable to the trial including but not limited to, the UK Clinical Trials Regulations, Medicines for Human Use (Clinical Trial) Regulations 2004, principles of Good Clinical Practice, the World Medical Association Declaration of Helsinki entitled 'Ethical



Appendix F: Participant information sheet



PARTICIPANT INFORMATION SHEET V3: 9th November 2011

You are being invited to take part in a research study called: **Discussing Sexuality after Traumatic Brain Injury: Perceptions of Health Professionals.**

Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully before deciding whether to take part. Take the time to discuss it with others if you wish, and please contact me if there is anything that is not clear or if you would like more information.

What is the study about?

This study is about sexuality after Traumatic Brain Injury (TBI). Sexuality is defined as “the way people experience themselves as sexual beings”, and includes sexual activity, attraction to other people as well as how we feel about our bodies. Research has found that around 50-60% of people notice some changes in their sexuality following their TBI, yet only 6% of health professionals ask service users about this on a regular basis. In this study I aim to explore health professionals’ experiences and perceptions of having discussions with service users after TBI.

Who can take part?

You are able to take part in this study if:

- You currently work with service users that have experienced a TBI
- You are willing to respond to open-ended questions pertaining to your personal experiences of discussing sexuality with service users, in a focus group.
- You consent to taking part in the study

What will I be asked to do if I take part and how long will it take?

If you agree to take part, you will be expected to attend a one-off focus group which will last around 1 ½ hours.

The focus group will consist of 5-8 people, who will get together to discuss the topic of sexuality and TBI. Focus groups are a useful way to find out what people think, as well as why they think that way. During the focus group I will encourage you to share experiences and opinions and comment on each-others experience.

The focus group will ideally take place at your usual place of work during hours of usual working practice (between 9am and 5pm). The discussion will be recorded using a digital audio recorder, so that it can be transcribed it afterwards (turned into written text). A transcription service may be used. In this case, the transcriber will be required to sign a confidentiality agreement to confirm that they will not share any information from the recordings.

What questions will you ask?

In the focus group you will be asked about your personal experiences of working with people who have experienced a TBI, including any discussions that you may have had (or not had) with them about sexuality. We will then think about some the reasons why health professionals may not discuss the issue of sexuality with clients, and finally think about the changes that could be made to help people to discuss the issue more openly and frequently.

It is important for you to know that there aren't any right or wrong answers – I am interested in hearing your opinions.

Will I be paid to take part?

Participants will not be paid to take part in the study. Participation is entirely voluntary.

If you are required to travel from your usual place of work (please note that this is not expected), then travel expenses to and from the focus groups will be reimbursed at 24p per mile. Public transport expenses can also be reimbursed. Refreshments will be provided.

What will happen to the data that is collected?

I will analyse the data from the focus groups using Thematic Analysis, which is a method used to pick out common themes and patterns in the things that people say.

With your permission, I will keep your contact details on record so that I can send you a summary sheet of the main findings once the study has been written up.

The results will be written up and submitted in October 2012 so that I can meet the requirements of the Doctorate in Clinical Psychology. In addition, I may submit the findings to a scientific journal, or present the findings at meetings or conferences. Every care will be taken not to include any information that could identify you personally. Some quotes may be used but you will not be identified through these.

How is confidentiality maintained?

In accordance with the Data Protection Act of 1998, all information and data will be kept confidential under safe storage at the University of Lincoln. Records will be kept here for 7 years after completion of the study.

Do I have to take part?

No, taking part is entirely voluntary. If you choose not to take part, you do not have to give a reason and no pressure will be out on you to try and change your mind. You can choose not to take part without incurring any penalty. In addition, please note that if you do initially agree to take part, you may change your mind at any point, and again you do not have to give a reason.

What are the possible benefits of taking part?

It is not expected that there will be any personal therapeutic benefit from taking part in the study, however some participants may find it interesting or helpful to talk to other staff who may have experienced similar things to themselves.

Your contribution will add to scientific knowledge about sexuality after TBI. It is hoped that this study will lead to changes being made within services to enable sexual problems to be discussed more openly, for example through the development of guidelines to advise staff on how to discuss the issue of sexuality with service users. This will contribute to the improvement of the overall care that service users receive following a TBI. It is also hoped that this study will provide a basis upon which further research could be developed.

What are the possible disadvantages of taking part?

In the focus group you will be asked to talk about and reflect on aspects of your own clinical practice, in front of other health professionals. Please note that you do not have to share anything that you do not want to. It is fine if you choose not to answer a question and you don't have to give a reason. In addition, you can choose to pull out of the discussion at any time without giving a reason.

What happens if I change my mind about taking part?

Participation in the study is voluntary. You can change your mind about taking part at any point. Please note that if you do decide to withdraw during the focus group, you can request that your data be destroyed for up to two weeks, by contacting Kerry Dyer (contact details below). Please note that after this, the data will have been transcribed and therefore your data cannot be destroyed as it will affect the data collected from the other participants.

Who is conducting the research?

This research is being conducted by Kerry Dyer, Trainee Clinical Psychologist on the Trent Doctorate in Clinical Psychology course. I have experience working as an Assistant Psychologist with people who have experienced TBIs, and have also worked with older people with memory problems. The primary supervisor for this project is Dr Roshan das Nair (Consultant Clinical Psychologist), who has experience of working in the areas of sexual health and brain injuries.

Has this study been ethically approved?

This study has been approved by the University of Lincoln's Research Ethics Committee and the Nottingham University Hospitals Research and Development Department. If you have any concerns regarding the design or conduct of this study then please contact The Research Ethics Committee: School of Psychology, University of Lincoln, Brayford Pool, LN6 7TS.

What do I do now?

Think about the information on this sheet, and please take the time to discuss it with other people if you wish. Please do contact me if you are not sure about anything or if you would like more information about the study.

If you do decide to take part, then please contact the nominated clinician in your multi-disciplinary team on the number below, who will be collating the details of health professionals that are interested in taking part. Your details will then be passed on to me, and I will then contact you to discuss the next step.

Contact Details

- **Name of Nominated Clinician (please fill in your details below):**

Telephone number:

Email:

- **Primary researcher:** Kerry Dyer
Email: 10197317@students.lincoln.ac.uk
Telephone number: 01522 886029
- **Research supervisor:** Dr Roshan das Nair
Email: roshan.nair@nottingham.ac.uk
Telephone number: 0115 846 8314

Thank-you for taking the time to read this sheet!

Appendix G: Participant consent form



PARTICIPANT CONSENT FORM v3: 9th November 2011

Title: Discussing Sexuality after Traumatic Brain Injury: Perceptions of Health Professionals.

Researcher: Kerry Dyer, Trainee Clinical Psychologist

Academic Supervisor: Dr Roshan das Nair, Consultant Clinical Psychologist

I confirm that as an informed participant of this study:

- I have read and understood the participant information sheet (v3) dated 9th November 2011.

- I have had an opportunity to consider the information on the sheet, ask questions and have had these answered satisfactorily.

- I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without penalty.

- I understand that if I decide to leave the study, I can request that any data is destroyed up to two weeks following the focus group. I understand that after this, the data will have been transcribed and therefore the data cannot be erased as it will affect that collected from the other participants.

- I agree for my contact details to be held on record so that I can be sent a summary of the main findings.

- I agree to take part in the above research study.

Participant's Name: _____

Signature: _____ **Date:** _____

Researcher's Name: _____

Signature: _____ **Date:** _____

Contact details

- **Primary researcher:** Kerry Dyer
Telephone number: 01522 886029
Email: 10197317@students.lincoln.ac.uk
- **Research supervisor:** Dr Roshan das Nair
Telephone number: 0115 846 8314
Email: roshan.nair@nottingham.ac.uk

This study has been approved by the University of Lincoln's Research Ethics Committee. If you have any concerns regarding the design or conduct of this study then please contact The Research Ethics Committee: School of Psychology, University of Lincoln, Brayford Pool, LN6 7TS.

Appendix H: Initial codes and themes

| Transcript | Initial codes | Initial themes |
|--|--|--|
| <p>I: So it sounds like you're saying it might not be appropriate to ask routinely after the injury or just straight after discharge, but maybe at a later stage?</p> <p>P1: Well I guess the problem is that initial assessment becomes the template to carry through for the whole of, of the sort of (.) the whole of the rehab intervention (.) and never get round to asking about sex and sexuality (.) or difficulties and changes that might have occurred. Erm</p> <p>P4: I think a routine- I think one way is having a standardised questionnaire where it's brought up, like the EQI. The European, what is it? The- European Brain Injury Questionnaire?</p> <p>P4: Yeah I think it's on that, so I think having something like that. What I was thinking when I was thinking about this was that is that I think it's an issue, a way around it surreptitiously bringing, I can't say it, can I?</p> <p>I: (laughs)</p> <p>P4: Surreptitiously (.) bringing it up. It's there as a question, so then it gives them</p> <p>R: Mmm</p> <p>P4: Permission to ask it cos you know that they know it's sort of, maybe a proper, I don't know if that's one way round it</p> <p>P1: So how do you then know? How would you get your suspicion if you know what I mean? How would you know when you were suspicious that there might be problems in that area (.) to bring up the questionnaire?</p> <p>P4: Well it's- (.) sometimes people hint at it don't they?</p> <p>P2: I think if they hint at it then we should [talk about it</p> <p>P4: [Then we should talk about it talk about it. Yes. Yeah</p> <p>I: Do you mean that sexual issues are, like, one question on a questionnaire that's more [general?]</p> <p>P4: [Yes, yeah</p> <p>I: So it gives them the opportunity to-</p> <p>P4: Yeah. To realise that that we're covering the whole issues. It may be a way. I'm not saying that's the way we'd address sexual issues but that might be a way of raising their awareness that there is a whole gannet of problems because often people don't realise that the problems that their experiencing are related to head injury <u>sometimes</u></p> <p>I: Yeah</p> <p>P4: And sometimes they're <u>not</u></p> <p>(.)</p> <p>P1: I think I'd also argue <u>that</u> err, and I'm probably guilty of this one as well that in a sense it's a bit like hiding behind a questionnaire</p> <p>P4: Yeah. Yeah. Yeah</p> <p>I: Mmm</p> <p>P1: It's like a sort of <u>shield</u> really</p> <p>P4: Yeah</p> <p>P1: To hide your own embarrassment or potential discomfort</p> <p>P4: Yeah</p> <p>P1: If you ask about it, and the client or the <u>family</u> respond in a way that might suggest that they think it's intrusive, what you're asking.</p> | <p>Challenge: assessment creates a template</p> <p>Facilitator: Questionnaire</p> <p>Questionnaire: to bring surreptitiously</p> <p>Facilitator: Questionnaire would give permission to ask</p> <p>Challenge: When to bring up the questionnaire?</p> <p>Defending viewpoint: Client will hint at problems</p> <p>Challenge: We should talk about it if they hint</p> <p>Agreement</p> <p>Facilitator: Questionnaire would raise awareness</p> <p>Facilitator: Questionnaire would raise awareness of link</p> <p>Reflection</p> <p>Challenge: Hiding behind a questionnaire</p> <p>Agreement</p> <p>Challenge: Questionnaire as a shield</p> <p>Barrier: Embarrassment/personal discomfort</p> <p>Intrusiveness</p> | <p><i>The best time to raise sexual issues</i></p> <p><i>Formal assessment tools</i></p> <p><i>You can't ask about sexuality directly</i></p> <p><i>Formal assessment tools</i></p> <p><i>Formal assessment tools</i></p> <p><i>Formal assessment tools</i></p> <p><i>Formal assessment tools</i></p> <p><i>Sexuality is a sensitive subject</i></p> |

Appendix I: Example of placing codes under themes

| | | |
|---|---|--|
| <p>Sexuality after TBI is a specialist issue</p> <p>Lack of knowledge, skills and expertise</p> <p>Lack of confidence in tackling medical issues Barrier: Not feeling confident, knowledgeable and experienced enough Facilitator: need to raise our knowledge Personal reflection; lack of knowledge Challenge: it's okay to say you don't know</p> <p>Confidence and comfort</p> <p>Reflection: I wouldn't be comfortable Comfort: lack of comfort Identifying problem: team having confidence Confidence; should have more confidence to address the issue</p> <p>Consultation, supervision and teamwork are important</p> <p>Personal experience: consulting sex clinic Supervision from sex clinic: contact infrequent Supervision: gaining advice is useful Team approach: can ask for advice Team approach: don't feel alone in managing it</p> <p>Education and staff training</p> <p>Training: lack of training about effects Training: not accessed Challenge: training is very basic Training: sex needs more formal training Training: sexuality not part of our training</p> | <p>Sexuality is a sensitive subject</p> <p>Risk of offending the service-user</p> <p>Intrusiveness Offending: don't want to upset/intimate them Offending: may lead to DNAs Offending: may affect participation in rehab Barrier: might scare them off Barrier: might affect therapeutic relationship Offending: client may shut down Religion and cultural barriers Religion: I have a presumption</p> <p>You can't ask about sexuality directly</p> <p>Subtly take opportunities to discuss sex Facilitator: questionnaire: to bring up surreptitiously Challenge: personal experience of bringing up sex directly</p> | <p>Practicalities of discussing sexuality</p> <p>The best time to raise sexual issues</p> <p>Timing: Asking may lead to worry Timing: inappropriate at an early stage We wait for hints Reflection: Wait for client to bring it Reflection: we sit back and wait for hints Challenge: assessment creates a template</p> <p>The best setting to discuss sexual issues</p> <p>Setting: one to one and privacy important Setting: seeing people in their own homes Helpline better than face to face Peer support</p> <p>Formal assessment tools</p> <p>Facilitator: questionnaire would give permission to ask Questionnaire: to bring up surreptitiously Challenge: service-users don't tick question Challenge: questionnaire as a shield</p> <p>Written information</p> <p>Written info: on organisations that might help Written info: on sexual positions Barrier: sexuality not in manual Facilitator: sign saying it's okay to ask Written info: empowering patients Challenge: leaflets are expensive Challenge: hiding behind written information</p> |
|---|---|--|

| Organisational and structural factors | Dilemmas about risk and vulnerabilities | Roles and responsibilities |
|---|--|--|
| <p>Sex is side-lined in rehabilitation</p> <p>Time: ward pressures Time: therapist versus clients agenda Sex not a priority: focus on pressing problems Sex not a priority: focus on walking and talking NHS: addressing sexuality is a luxury NHS: it's not out there</p> <p>A lack of specialist services</p> <p>Referring on: where to? Can of worms: who can deal with it? Can of worms: you will have to deal with it Can of worms: who will deal with it long term? Referring on: normal marriage counselling not appropriate Challenge: many organisations available</p> <p>Clinical environment of inpatient setting</p> <p>Clinical environment: don't realise problems until at home Clinical environment: partners don't spend time together Challenge: many go for graded discharge</p> <p>Sexuality not included on outcome measures</p> <p>Overwhelmed with outcome measures Outcome measures: sexuality (and QoL) not included No consequences: no-one will take us to court</p> | <p>Hypersexuality and disinhibition</p> <p>Giving advice: client could get in trouble Giving advice: clients may misinterpret advice Clients Don't see consequences of actions Sexual banter difficult to control Challenge: only a minority disinhibited Reactive management: deal with it when it arises</p> <p>Abuse and exploitation</p> <p>Risk: at risk due to TBI Personal experience: safeguarding incident Risk and vulnerability: clubbing Risk and vulnerability: internet Reactive management: Not a problem unless it increases risk Challenge: but he's putting himself at risk</p> <p>Professionals may be vulnerable</p> <p>Advances to staff have been made Reactive management: inappropriate behaviour to staff Risk: crossing professional boundaries Risk: could be seen as unprofessional Risk: vulnerable to accusations</p> | <p>Who: it should be the OT's role Who: specialist counsellor's role Who: medics for physical aspects Who: depends on the problem Who: Client's choice who they speak to Justification: it's not in our job description</p> <p>Everybody's business is nobody's business</p> <p>Barrier: expect someone else to do it Barrier: it's a job for somebody else Bottleneck: nobody is asking about it Roles: everybody's business is nobody's business</p> <p>Therapeutic alliance is important</p> <p>Roles: depends on the relationship Roles: someone they know well should raise it Alliance: have to build rapport with client Alliance: close relationship helps Alliance: clients open up if you build rapport Barrier: know them too well? Challenge: being close = being vulnerable</p> <p>Gender mismatch</p> <p>Gender: male to female advice is difficult Gender: would pass on to female Gender: same body parts Gender: female staff and male clients common Challenge: gender not always related</p> |

Appendix J: Early version of thematic map

