Exploring occupational therapists’ experiences of addressing sexual activity with stroke patients
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ABSTRACT

**Purpose:** Engagement in sexual activity is a common problem for people following a stroke and is an area often neglected in stroke rehabilitation. There is little evidence exploring the role of occupational therapy in addressing sexual activity with stroke patients, particularly in an Irish context. This study advances the understanding of the meaning of sexual activity for occupational therapists along with their attitudes, roles and experiences of addressing sexual activity with people following a stroke. The study highlights reasons that influence occupational therapists’ decisions about whether to address it in practice.

**Method:** A qualitative study was conducted using a descriptive explorative approach to describe and explore the occupational therapists’ experiences. Data were collected through individual semi-structured interviews with occupational therapists working in stroke rehabilitation services (n=7). Interviews were audio-recorded, transcribed and analysed using qualitative thematic analysis. Credibility and trustworthiness were strengthened through member checking, supervision, a reflective journal and an audit trail.

**Findings:** The four key themes that emerged from the data were; broad views of sexual activity, occupational therapists’ approach to sexual activity, barriers in practice and deciding factors. These themes are supported with direct quotations from the participants.

**Conclusion:** Occupational therapists in the study had a broad view of sexual activity and considered it to be within the remit of the profession. However they were poorly trained, adopted a passive role in practice and decided whether to address sexual activity based on their own beliefs. Recommendations for practice and future research are discussed.

**KEYWORDS:** Sexual activity; stroke; occupational therapy; rehabilitation; occupation.

**WORD COUNT:**
INTRODUCTION

Fifteen million people suffer a stroke worldwide every year with one third of those being left permanently disabled (World Health Organisation (WHO), 2002). It is the most common cause of major physical disability in Ireland (Irish Heart Foundation, 2008).

The World Health Organisation (2006) defines sexuality as a central component to the human experience that encompasses gender identities, sexual orientation, intimacy, eroticism, pleasure, sex and reproduction and considers sexual activity as merely the act of sexual intercourse. There are many definitions relating to the topic used interchangeably within occupational therapy literature and there is no consensus as to the correct term in use. Sexuality has been defined as simply engagement in sexual activities and being part of a sexual relationship (Sakellariou & Algado, 2006). Couldrick (2005) uses the term sexual expression to encompass sexual health, sexuality and sexual functioning. Sexual activity is the term used by the American Occupational Therapy Association and is defined as “engaging in activities that result in sexual satisfaction” (American Occupational Therapy Association(AOTA), 2008, p.631) and is the chosen term in this study.

The World Federation of Occupational Therapists states that the core purpose of occupational therapy is to ‘enable people to participate in the activities of everyday life’ (World Federation of Occupational Therapists (WFOT), 2011, p. 1). The American Occupational Therapy Association (2008) lists sexual activity as an activity of daily living (ADL). This implies that it is within the scope of practice of occupational therapy. Occupational therapists view humans as occupational beings and are concerned with promoting health and well being through participation in meaningful occupations (Pierce, 2003). Occupational therapists play an important part in the rehabilitation process by enabling stroke survivors to participate in meaningful activities through a combination of restoring skills and offering compensatory strategies (Sabari & Lieberman, 2008).

Research shows that stroke patients experience a decline in sexual activity and sexual satisfaction (Edmans, 1998). Sexuality is a fundamental part of human existence and has been linked to quality of life (Northcott & Chard, 2000). It can be expressed through many occupations such as flirting, dating, putting on make-up, cooking for one’s partner or engaging in sexual intercourse (Sakellariou & Algado, 2006).
Despite this, studies show that an area often neglected in stroke rehabilitation is the return to normal sexual activity. There is an ambiguous picture within the occupational therapy literature as to whether addressing sexual activity is within the domain of the profession. Occupational therapists consider themselves to be holistic care providers who enable participation in meaningful occupations; thus, sexual activity cannot be excluded from practice (Novak & Mitchell, 1988; Pollard & Sakellariou, 2007). Couldrick (2005, 1998) believes that sexual activity should hold the same importance in occupational therapy practice as personal care, work and leisure, as it may be of greater importance to the individual. In contrast, a lead figure in occupational therapy, Gary Kielhofner was of the opinion that sexual activity is not occupational in nature and therefore not within the remit of occupational therapy (Kielhofner as cited in Couldrick, 2005).

The importance of sexual activity for people with disabilities is a common topic in the media at present, highlighting that the desire to engage in sexual activity is the same whether somebody has a disability or not. This study focuses on occupational therapists’ experiences of addressing sexual activity with stroke patients. The impetus for the study arose from the researcher’s first-hand experience of working with stroke patients during practice, where she observed that sexual activity was not being addressed at all. From speaking to patients, it was apparent that sexual activity was of concern to them. The researcher noted the inconsistencies to addressing sexual activity within the setting.

**LITERATURE REVIEW**

Literature was sourced from online databases, through hand searching of journals and by examining citations in recently published studies. The primary databases included CINAHL, Ingenta, PubMed and OTDbase. The majority of the studies accessed were international studies as there is a paucity of Irish research in relation to this topic. The studies in the literature review were published between 1997-2014 (see Appendix 1). The key words searched included “stroke” AND “sexual activity” and “occupational therapy” AND “sexual activity”.

*Sexual activity following a stroke*

Research has highlighted the negative effects of stroke on sexual activity. Korpelainin, Niemenen and Myllylä (1999) in a quantitative study of 192 stroke
patients reported a significant decline in libido and decreased frequency of sex, with 33% of patients reporting having ceased sexual intercourse post-stroke. A Turkish study used a questionnaire to investigate the sexual functioning of 103 stroke patients and found a statistically significant difference between pre and post-stroke frequency of sexual intercourse and satisfaction with sexual life among the participants (Tamam, Tamam, Akil, Yasan and Tamam, 2008). Similarly, Seymour and Wolf (2014) using a cross-sectional study found that individuals with mild stroke experienced decreased participation in sexual activity post stroke. Across all studies, it is predominantly psychosocial factors that influence engagement in sexual activity following a stroke, rather than medical. The importance placed on sexual activity by the patient, the fear of a recurrent stroke, reduced sexual function and the difficulty of discussing sexual issues with a partner were factors that contributed to these problems (Buzzelli, di Francesco, Giaquinto and Nolfe, 1997; Korpelainin et al., 1999). A survey of 38 stroke patients in America found that 71% identified sexuality as a moderately to very important issue in stroke rehabilitation (Stein, Hillinger, Clancy & Bishop, 2013). Taman et al. (2008) found that sex was regarded as significantly more important for males (84%) than females (10%). As Turkey is a male dominated country, this significant gap between genders may be due to cultural factors (Tamam et al., 2008). The physical incapacity of the stroke patient resulting in positioning problems during sex was also found to impede the resumption of normal sexual activity (Edmans, 1998). Moreover medical issues such as depression and medication have been linked to sexual dysfunction in stroke patients (Korpelainin, Nieminen & Myllylä, 1999).

The patient’s perspective of sexual rehabilitation

The provision of intervention addressing sexual activity as part of rehabilitation can be beneficial for the patient and their partner. Song, Oh, Kim and Seo (2011) introduced a sexual rehabilitation programme for stroke patients and their spouses, which included information, strategies and counseling on resuming a normal sexual life. The programme significantly increased sexual satisfaction and frequency of sexual activity amongst the participants who engaged in the programme compared with the control group who did not (Song et al., 2011). Northcott and Chard (2000) explored clients’ experiences of sexual rehabilitation using qualitative in-depth interviews. The majority of participants believed sexual activity should be discussed
routinely as part of rehabilitation, suggesting the healthcare professional with the closest relationship with the client was most appropriate. Those who had received intervention around sexual activity were satisfied with the treatment and emphasised the importance of such intervention (Northcott & Chard, 2000). A 2014 study investigating the lives of 196 stroke survivors in Ireland reported that difficulty with intimacy was affecting relationships and one quarter wanted more information on resuming physical relationships (Horgan, Walsh, Galvin, Macey & Loughnane, 2014). Similarly, Edmans (1998) found that stroke patients and their partners wanted more opportunities to discuss sexual activity. The participants specifically looked for information on why sexual changes occur and strategies regarding positioning (Edmans, 1998). These studies support the view that intervention around sexual activity should be part of routine care for stroke patients.

*Sexual activity as an area of concern for occupational therapists*

Some studies show that occupational therapists consider addressing sexual activity to be within the scope of the profession (Couldrick, 1998; Yallop & Fitzgerald, 1997). Couldrick (1998) investigated the occupational therapy role through qualitative interviews and found that positioning, provision of equipment, education and emotional support were the most common interventions provided. Role perception can depend on occupational therapists level of comfort with situations and the extent to which they challenge their values and beliefs (Yallop & Fitzgerald, 1997). Penna and Sheehy (2000) found that therapists with greater experience were more likely to consider it to be within the domain of occupational therapy ($p < 0.05$). Despite therapists considering sexual activity to be a legitimate area of concern for the profession, it is rarely discussed with patients (Haboubi & Lincoln, 2003). A recent study undertaken by Hyland and McGrath (2013) examined the attitudes and beliefs towards addressing sexual activity amongst 58 practising occupational therapists in Ireland using a cross-sectional internet-based survey. The majority of participants (88%) regarded sexual activity as a legitimate area of concern for occupational therapists, however, 62% rarely or never discussed sexuality in therapy. This highlights the clear gap between occupational therapy’s professional ideology, which recognises its role within sexual activity, and everyday practice (Couldrick, 1998; Hyland & McGrath, 2013).
Barriers to addressing sexual activity have been identified in the literature. A lack of knowledge and training inhibits occupational therapists from addressing sexual activity in practice (Yallop & Fitzgerald, 1997). Jones, Weerakoon and Pynor (2005) surveyed 340 occupational therapy students in Australia and found that over half of the participants believed their education did not deal with sexual issues. However, it must be noted that all participants were enrolled at the same institution. McLaughlin and Cregan (2005), looked at the experience and comfort of health professionals, including occupational therapists, in addressing sexual issues with stroke patients. Although 9 out of the 13 participants had been asked for advice on sexual issues, the majority did not feel they had adequate training in the area and routinely provided patients with a booklet or referred to other services. The lack of knowledge and training along with a fear of embarrassing the patient were identified as the main barriers (McLaughlin & Cregan, 2005).

Many occupational therapists see it as a sensitive area of practice and lack confidence in their ability to address it respectfully (Hyland & McGrath, 2013). Couldrick (1998) interviewed 10 occupational therapists who expressed a lack of confidence in their ability to address sexuality in a respectful and sensitive way. However, Penna and Sheehy’s (2000) findings did not reflect these opinions and did not see it as an area that is too sensitive to address. Yallop and Fitzgerald (1997) suggested that occupational therapists level of comfort depended on the power and control they had over a situation. Using a multi-method design which included a scenario instrument, they discovered that participants were more comfortable providing practical advice that could be drawn from knowledge and experience, such as positioning and equipment.

McGrath and Lynch (2013) identified socio-cultural issues as a barrier to addressing sexual activity in practice. Occupational therapists thought of sexuality as a ‘taboo’ subject, particularly for older people in Ireland and feared it would cause offense or embarrassment to clients if brought up in therapy. A previous study by Hyland and McGrath (2013), found that the influence of the Catholic church impacted on occupational therapists’ readiness to address sexual issues in practice. The influence of culture was also raised in an earlier study by Couldrick (1999) who identified the lack of a universally accepted language around sex and ethical boundaries as barriers.
In conclusion, it is evident that sexual activity is negatively affected by stroke. Patients have expressed their wish to have sexual activity addressed as part of rehabilitation. There are conflicting views within the literature as to whether addressing sexual activity is a domain of concern for occupational therapists. The literature highlights the gap between ideology and practice, where although occupational therapists believe addressing sexual activity is within their role, many do not incorporate it into daily practice. Barriers identified include occupational therapists’ comfort level, personal attitudes, knowledge, resources and socio-cultural factors. While the majority of existing studies in the area of occupational therapy and sexuality have shown the extent to which occupational therapists feel inadequately prepared, the majority of them used quantitative methods. Many of the survey designs ruled out the possibility of discovering other factors that impact on the implementation of sexual activity as part of treatment. Furthermore, there is a dearth of research in the area of occupational therapists addressing sexual activity in the Irish context. This study expands on the recent work by Hyland and McGrath (2013) and McGrath and Lynch (2013) while offering new perspectives of occupational therapists working specifically with stroke patients in Ireland.

RESEARCH QUESTION

What are occupational therapists’ experiences of addressing sexual activity with stroke patients?

RESEARCH AIMS

The primary aim of this study was to explore occupational therapists’ experiences of addressing sexual activity with stroke patients in Ireland. Objectives developed from this aim were as follows:

- To gain a deeper understanding of the meaning of sexual activity to occupational therapists.
- To gain a deeper understanding of occupational therapists’ opinions, experiences and roles of addressing sexual activity with stroke patients.
- To identify factors that inhibit or promote the addressing of sexual activity with stroke patients.
RESEARCH DESIGN

Methods

A qualitative methodology using a descriptive explorative approach was adopted in this study to explore and describe the experiences of the occupational therapists in addressing sexual activity with stroke patients. As little is already known about this phenomenon in the Irish context, a qualitative approach was chosen as it has been advocated as the most effective way to explain a new or under researched area (Polit & Beck, 2004). Qualitative research facilitated the researcher to gain an in-depth understanding of the participants’ experiences (Parahoo, 2006). A descriptive explorative approach provides both a rich description of the subject matter (Sandelowski, 2000) and an exploration of the occupational therapists’ experiences, whose perspectives have not been researched previously (Carpenter & Suto, 2008).

Participants

The researcher recruited a purposive sample of 7 occupational therapists working within stroke rehabilitation services in the South and East of Ireland. Purposive sampling involved deliberately choosing participants that would provide the most important information for the study (Carpenter & Suto, 2008) and ensured participants were recruited from a variety of services including in-patient stroke units, community stroke services and stroke clinics (Bryman, 2008). The researcher made direct contact through email with potential participants to outline the study and invited them to participate. Interested participants were provided with an introduction letter formally inviting them to participate in the study (see Appendix 2) along with an information sheet that outlined the aims of the study, the rights of the participants, discussion on confidentiality and contact details of the researcher (see Appendix 3). The sample size was selected as it was deemed appropriate to generate sufficient data for the scope of the study (Carpenter & Suto, 2008). Pseudonyms will be used to ensure confidentiality (see Table 1).

The inclusion criteria were:
1) Qualified occupational therapists.
2) Minimum experience of one year working in stroke rehabilitation to ensure the collection of rich data.
The researcher ensured that participants were not all working in the same setting to ensure variety.

Table 1: Participant demographics

<table>
<thead>
<tr>
<th>Participant</th>
<th>Eamon</th>
<th>Laura</th>
<th>Ciara</th>
<th>Alana</th>
<th>Siobhan</th>
<th>Rachel</th>
<th>Orla</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
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<td>Female</td>
<td>Female</td>
<td>Female</td>
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</tr>
<tr>
<td>Age</td>
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<td>26-35</td>
<td>26-35</td>
<td>26-35</td>
<td>26-35</td>
</tr>
<tr>
<td>Years Qualified</td>
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<td>19</td>
<td>4</td>
<td>3</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Years working in stroke rehab</td>
<td>16</td>
<td>14</td>
<td>13</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Completed extra training</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Type of rehab setting</td>
<td>Community in-patient</td>
<td>Primary, Community &amp; Continuing Care</td>
<td>Community in-patient</td>
<td>In-patient rehab</td>
<td>In-patient rehab</td>
<td>In-patient rehab</td>
<td>In-patient rehab</td>
</tr>
</tbody>
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Data Collection

Each participant took part in one individual semi-structured interview that lasted between 30-50 minutes in a quiet room at their place of work to ensure confidentiality. In qualitative research, the researcher is the tool by which data is collected (Carpenter & Suto, 2008). In-depth semi-structured interviews were considered to be the most appropriate method of data collection for this study as the aim was to elicit the occupational therapists’ personal experiences while also
maintaining a descriptive explorative approach (Sandelowski, 2000). This method was deemed more appropriate than completely structured interviews to allow the researcher to follow up on the participant’s opinions so as to not to miss out on valuable information. The use of focus groups was dismissed due to the large geographical distribution of participants. An interview guide of six questions and corresponding probing questions was constructed from information gleaned in the literature review (see Appendix 4). Participant demographics were collated prior to the interview starting. The interviews were audio-recorded and transcribed later to minimise the distraction for the interviewee (Polit & Beck, 2004). However, field notes were taken immediately after each interview to record any observations or information that arose after the interview had ended. The researcher conducted a pilot interview with a family member prior to data collection to check the data collection and analysis strategies of the study (Parahoo, 2006). The pilot study proved useful to trial the question guide (Carpenter & Suto, 2008) and identified areas where opportunities were missed to ask the participant for further detail. Data from the pilot study were not included in the study. The study was conducted over a 10-month period (see Appendix 5).

Data Analysis

Data were analysed as they were collected using qualitative thematic analysis to describe and explore the occupational therapists’ experiences, as described by Carpenter and Suto (2008). Transcripts were read and re-read to develop a close familiarity with the data. Data were organised into more manageable units or categories through the process of coding which involved labeling similar pieces of data (Carpenter & Suto, 2008) (see Appendix 6). Potential subthemes were generated from the codes. Finally, the researcher identified themes from these subthemes, which are reported in the findings along with direct quotations from the data.

Trustworthiness

To ensure the rigour of the study, trustworthiness strategies were employed. Lincoln and Guba (as cited in Finlay, 2006) defined the main principles of trustworthiness in qualitative research as credibility, dependability, confirmability and transferability. All significant findings including conflicting opinions from the participants who have varied work settings and experiences aid in providing a true picture of the
phenomenon and strengthens the credibility of the study (Carpenter & Suto, 2008). Participants were given the opportunity to engage in member checking to verify the data and ensure that their experiences are accurately represented (Curtin & Fossey, 2007). Confirmability can be achieved through reflexivity, a process useful to evaluate how the researchers views and perceptions shape the research process (Carpenter & Suto, 2008). The researcher kept a reflective diary for the duration of the study and reflected on information collected in the diary and field notes during the data analysis stage to ensure the information interpreted from the data has not been influenced by researcher bias. An audit trail was maintained by the researcher and reviewed during regular meetings with her supervisor to ensure dependability (Finlay, 2006). To aid transferability, a detailed description of participants in the study is provided.

**Ethical Considerations**

Ethical approval was obtained in December 2013. Informed consent involves making sure that participants understand any risks and potential benefits of participating in a study (Parahoo, 1997). Informed consent was obtained from the participants by reading and signing the consent form prior to the study commencing and participants were reminded that they had the option of withdrawing from the study at any time without repercussions (see Appendix 7). Confidentiality was respected by ensuring pseudonyms were used and any identifiable information was not recorded in the data. All data relating to the study is stored in locked files on the researcher’s laptop or in a locked cabinet and are only accessible by the researcher. All data will be destroyed within 13 months, which is in accordance with the Data Protection Acts 1988 and 2003.
FINDINGS

Four principle themes, based on 11 subthemes were generated from the data (see Table 2).

Table 2: Themes

<table>
<thead>
<tr>
<th>Sub-themes</th>
<th>Themes</th>
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<tbody>
<tr>
<td>More than the act of sexual intercourse</td>
<td>Broad views of sexual activity</td>
</tr>
<tr>
<td>Encompasses intimacy, relationships &amp; idea of self</td>
<td></td>
</tr>
<tr>
<td>Fits with values of profession and skills</td>
<td>Occupational therapists’ approach to sexual activity</td>
</tr>
<tr>
<td>Passive role adopted</td>
<td></td>
</tr>
<tr>
<td>Advocate a team approach</td>
<td></td>
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<tr>
<td>Socio-cultural norms</td>
<td></td>
</tr>
<tr>
<td>Patient discomfort</td>
<td>Barriers to practice</td>
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<tr>
<td>Therapists’ perceived readiness</td>
<td></td>
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<tr>
<td>Patient’s age and relationship status</td>
<td>Deciding factors</td>
</tr>
<tr>
<td>Priority given by patient</td>
<td></td>
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<tr>
<td>Discussion initiated by patient</td>
<td></td>
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</table>
Broad views of sexual activity

More than the act of sexual intercourse
The interviews began by exploring the notion of sexual activity and occupational therapy in its broadest form and thus providing an insight into its meaning for the participants. Participants were of the opinion that the concept of sexual activity was “a much broader thing” (Eamon) and encompassed more than just the act of sexual intercourse alone:

*It’s not necessarily sexual, it’s intimacy…it can be caressing and massaging and touching, it doesn’t have to be full sexual intercourse (Ciara)*

*Not just around like the sexual act, kind of a person’s perception of themselves and like roles within relationships.” (Siobhan)*

Encompasses intimacy, relationships & idea of self
There was a general consensus among the participants that intimacy between people, relationship building and people’s perception of themselves including self-confidence and self-image were imperative to sexual activity. They saw ‘the recreation of self’ (Orla) following a stroke as the starting point to addressing sexual activity in practice:

*You can do an awful lot around body image and self-efficacy to help the person then, with their relationships (Rachel)*

Additionally, the idea of roles and how they shape relationships was a common topic of discussion:

*It’s more about you know being the provider, being the person who looks after things in the house…that kind of male female kind of divide (Siobhan)*
Occupational therapists’ approach to sexual activity

Fit with values of profession and skills

A theme that emerged from participant’s responses was the approach taken by occupational therapists in addressing sexual activity with stroke patients. Participants believed that sexual activity was an ADL and therefore came under the occupational therapy remit:

*I suppose it’s like any other activity if somebody whether they want to lie on their side and hug their husband...it’s something they want to be able to do, it’s an ADL* (Laura)

*Well it’s an occupation...it is part of occupational performance* (Rachel)

Participants identified that occupational therapists already possess key skills such as communication, assessment and activity analysis skills that would be needed to address sexual activity:

*OT certainly have the skills to be able to do the activity analysis and do the analysis of the person’s physical functioning...to enable somebody towards that sexual activity* (Orla)

*OT’s, we’re naturally sincere, communicative and active listeners and that’s a big part of it, being an active listener* (Ciara)

On the contrary, two participants raised the concern that “everything’s potentially within the role of OT” (Orla) and that the profession needs to be careful not to try and do everything:

*I think the worry is that OT’s try to be a ‘Jack of all trades, master of none’...as a profession we can sometimes dilute ourselves too much and try to do everything* (Rachel)
Passive role adopted
The majority of participants took a passive role in addressing sexual activity. Only two of the participants engaged in direct interventions with patients while the remaining participants most often referred patients to other professions and considered their role as a “gateway to link in with other services” (Laura):

\[ I \text{ had a younger guy recently who was only like 18...he had a girlfriend and he wanted to address the area so like he gave that to me so I approached her (psychologist) with it (Alana) } \]

\[ \text{Then there’s the sexual health nurse and it’s passed on that way but that again it’s just ’passing the buck’ (Siobhan) } \]

Advocate a team approach
All of the participants advocated for a team approach in addressing sexual activity:

\[ \text{Well I think it’s a mix of everyone. I don’t think it’s one person’s profession to deal with it, it has to be a team approach (Alana) } \]

\[ \text{I think it has to be a team approach...there’s physiological and that’s going to be from a nurses point of view, you then have the physical and either a physio or OT could potentially look at that (Orla) } \]

However two of the most experienced participants have never heard the topic discussed at a team meeting:

\[ \text{I can’t recall a MDT meeting where somebody is going we really haven’t addressed this mans sexual needs or you know his relationship (Eamon) } \]

Barriers to practice

Socio-cultural norms
Three key reasons why participants were discouraged from addressing sexual activity emerged from the data. These include the socio-cultural context in Ireland, a lack of knowledge and training and a fear of making a patient uncomfortable. In general,
participants felt that Ireland has culture whereby people do not openly talk about sex and would therefore see it as a subject that could cause discomfort:

*There is a history or culture in Ireland where people don’t talk about sex particularly with an older age group. It’s not an open topic of conversation (Orla)*

One participant spoke of the influence of the Catholic Church in Ireland on older generations and how it shapes their attitude towards discussing sexual activity:

*Certainly my generation, I’m 58 right now. We’d have grown up in a country where there was massive control of the Catholic Church and the only sin in the country was anything to do with sex. I would think most of the clients that we’re seeing would share the same culture (Eamon)*

Two participants who have worked abroad in England and the United States of America compared their experiences to Ireland and recall less of a cultural barrier:

*I think culturally I’ve learnt in the States we’re much more open. Here in Ireland it’s a Catholic country…there’s religious beliefs, there’s cultural beliefs and so I find that it’s not approached at all (Ciara)*

**Patient discomfort**

Participants were concerned that broaching sexual activity with patients would make them feel uncomfortable or embarrassed:

*You don’t want to push somebody if they don’t want to talk about it because I know some people might be embarrassed and they might not want to speak about it (Laura)*

*If I feel that it’s an area they shy away from and they don’t want to talk about it I wouldn’t bring it up (Rachel)*

Orla expressed her concern that addressing sexual activity could have a negative impact on the therapeutic relationship:
Not everyone is going to be comfortable discussing it...it has the potential to impact your therapeutic relationship quite negatively if they’re not comfortable with it.

Therapists’ perceived readiness
A subtheme that arose during the interviews was the participant’s lack of perceived readiness to address sexual activity in practice due to inadequate levels of knowledge and training with 6 out of 7 participants stating the topic wasn’t covered in undergraduate training:

Like lack of training in it. I feel no one has said in college sexual activity this is our role this is how we go about doing it...I’ve worked in like 4 different settings now and it has not been addressed so I just don’t feel I would have the confidence to deal with it (Alana)

I wouldn’t know what to do...I’d prefer to have some skills and some idea and some preparation (Eamon)

Participants would like training on how to address it and more research so there is “more kind of evidence base behind our role” (Alana):

It’s something I would like to have more training on because it’s a sensitive topic...I think I’d need more training how to broach it with people (Siobhan)

Deciding Factors

Patient age and relationship status
An emerging theme was factors used to decide whether participants would address sexual activity with patients or not. In general, participants were deciding whether to address this area of practice based on the client’s relationship status or age. Participants were more likely to address sexual activity with young people who are married or in a relationship:

People who are married or in a relationship because if I know that there’s no one in their life that could be a sexual partner or something I don’t address it with them (Ciara)
It might be a bit ageist but with younger people as well I’d be more inclined, I’d be more conscious of working with them and being aware of their social history and if they had a husband or wife or partner (Siobhan)

Lack of priority

Participants were not addressing sexual activity as it is down the list in terms of priorities for people (Orla) and is not something that is the focus of their rehabilitation goals:

The patients don’t put as much weight on it to begin with like…if you do a COPM (Canadian Occupational Performance Measure) with the person usually one of the last things they would talk about is sexual activity. I think its prioritisation really (Rachel)

It’d be very much I want to be able to get up and walk, I want to be able to dress…it wouldn’t be until later that these issues would come up (Laura)

Discussion initiated by patient

Participants would be encouraged to address it in practice if the client initiated the discussion:

Really just being led by the patient. If they guide the discussion that way or make reference to it…I would try and explore it from that (Siobhan)

One participant went so far as to say that the onus is on the client to raise the issue “This is my opinion but you know the fact that if they wanted it addressed they could approach me about it” (Alana) In contrast, Rachel states that “it’s not waiting on the client to ask but for you to pick up on it.”
DISCUSSION

The purpose of this study was to explore the experiences of occupational therapists in Ireland in addressing sexual activity with people following a stroke. The study confirms the findings of earlier studies regarding occupational therapy practice in this area while also providing new insights. The findings in this study contribute to the growing body of knowledge about occupational therapy and intervention in sexual activity.

To understand the occupational therapy role in addressing sexual activity with stroke patients, there needs to be clarification on the term in use within the profession and what it encompasses. This study helped to enlighten what practising occupational therapists considered sexual activity to include. Participants believed that the meaning of sexual activity was broad and encompassed intimacy, relationships, roles and the notion of self and not just the act of sexual intercourse. They saw the starting point of addressing sexual activity with stroke patients to be about the recreation of self, following a stroke. However there is no consensus as to the term in use with participants using a variety of related terms during the interviews. It is recommended that a grounded theory study be conducted to develop the concept of sexual activity in occupational therapy to ensure clarity (Parahoo, 2006).

All participants agreed that occupational therapy had a role in addressing sexual activity. They believed that it was compatible with the ethos of the profession and the core skills of an occupational therapist (Couldrick, 1998). They stated that as sexual activity is an ADL and if it is something a patient wants to be able to do then it is within the remit of the profession. However, concerns were raised that occupational therapy tries to get involved in everything, suggesting uncertainty around their role and possible reluctance to get involved. Occupational therapists in this study do not think it is solely their role and advocate for a whole team approach, highlighting the complex needs of stroke patients as physical, physiological and cognitive behavioural. Occupational therapists in McGrath and Lynch’s (2013) study also recognised that issues might arise that would be outside the profession’s remit and could see the need for a team approach. The recommendation of a team approach was not a strong finding in previous studies. Usually in the complexity of needs with stroke patients a comprehensive team
approach would be advocated in the patients journey. In keeping with previous studies that show that it is not only occupational therapists who are neglecting this area of practice (Haboubi & Lincoln, 20003; McLaughlin & Cregan, 2005), the most experienced participants had never heard the topic raised in a multi-disciplinary team meeting. There is a danger that without a definite role clarification, all team members could view sexual activity as a ‘team approach’ with no one team member taking responsibility and the issue not being addressed at all. To avoid this, sexual activity needs to be discussed in multi-disciplinary team meetings.

The findings of this study support the evidence from the reviewed literature that there’s a disparity between occupational therapists’ ideology and actual practice when it comes to addressing sexual activity (Hyland & McGrath, 2013; Couldrick, 1998). Although they see it as within the remit of the profession, participants took a passive approach to addressing sexual activity in practice and appeared content for other health professionals to deal with it or to refer patients on to other services. It appears that the participants were not claiming the role that they believed they had. Similarly Haboubi and Lincoln (2003) in a study of multi-disciplinary health professionals, occupational therapists rated themselves lowest out of five professionals as to who should address sexual activity. The perception of the role changed according to the role on a team or other skills on the team (Yallop and Fitzgerald, 1997). For example, four participants had a sexual health nurse on site and saw their primary role to refer to her compared to two other participants who carried out direct intervention with patients.

This study sheds some light on reasons for this gap and identified three main barriers in practice. The findings highlight the strong influence of culture and religion in Ireland, particularly for older people in our society and the extent to which socio-cultural norms influence the actions of occupational therapists in addressing sexual activity. The addressing of sexual activity by participants in this study was compromised by their belief that sexual activity was not an open topic of conversation according to societal norms and did not think clients would want to discuss it. Similar findings were reported by McGrath and Lynch (2013), who felt it was a private matter for older people in Ireland and such discussion was likely to cause offence or embarrassment. Interestingly, participants who had practised abroad had not experienced this cultural barrier and it is not a strong theme in literature from
outside of Ireland. Thus, it appears that this cultural barrier is unique to Ireland. This suggests the need for occupational therapists to challenge their own cultural background, becoming aware of their own values and beliefs and how they impact on patient care.

Occupational therapists are concerned that if they bring the topic of sexual activity up it may make patients feel uncomfortable and impact negatively on the therapeutic relationship. This concern has been raised by the majority of healthcare professionals in research to date (McLaughlin & Cregan, 2005). Considering their beliefs of culture in Ireland, it could be said that occupational therapists are respecting the cultural norms of Irish people. However, there is no research to support this from the stroke patients’ viewpoint.

Participants in this study did not perceive themselves to be ready to address sexual activity due to inadequate levels of knowledge and training. As a result they did not know what they would do to help a person resuming sexual activity. Occupational therapists would like more training on how to discuss sexual activity in a way patients would find comfortable (McLaughlin & Cregan, 2005; Hyland & McGrath, 2013). Findings from this study and Jones et al. (2005) highlight that it is not an area of practice covered during undergraduate training or during post-graduate continued professional development and both students and practitioners are inadequately prepared. It is evident that training needs to be targeted at both practising occupational therapists and undergraduate students. Additionally, there is a need for research into the occupational therapy role and the efficacy of interventions.

Findings uncovered that the participants are deciding whether to address sexual activity with a patient based on their own preconceived ideas. In alignment with Hyland & McGrath (2013) participants were of the opinion that it should be confined to young married couples. They are making their own assumptions that older people and those not in a relationship would not need this addressed. However, it is clear that older people are sexually active.

Generally participants only addressed sexual activity if the patient brought it up with one participant stating that the onus is on the patient to initiate the discussion if they want it addressed. This raises the question if it is like any other ADL, why is not addressed the same? This could be as a result of a fear of making the client feel uncomfortable. However, a study by Northcott and Chard (2000) would suggest that
patients would like to be approached and made aware that advice is available if they needed it. 
In addition, participants did not think sexual activity was priority for patients in stroke rehabilitation and therefore were not addressing it. This finding conflicts with previous studies that show it is a very important issue in context of overall stroke recovery (Stein et al., 2013) and patients want it discussed routinely as part of rehabilitation (Northcott & Chard, 2000). However, the importance placed on sexual activity by patients has been linked to cultural factors previously (Tamam et al. 2008). Perhaps patients do not prioritise it as a rehabilitation goal because it is not brought up by occupational therapists? Overall, it seems that because occupational therapists do not have adequate knowledge and training they are left to use their preconceived ideas to guide practice. It is difficult to understand the perspectives of stroke patients in Ireland as limited research has been conducted. It is imperative that research is conducted to find out what stroke patients want in relation to resuming sexual activity in stroke rehabilitation.

**LIMITATIONS**

The researcher recognises that the study has some limitations including her lack of research experience. However the guidance of the supervisor ensured that the study was conducted in convention with qualitative research methods. While the interviews generated rich data, it is likely the experiences are unique to their contextual situations. The sample included four participants who worked in the same setting where there is a specialist sexual health nurse on site, possibly contributing to the passive role adopted by those participants. Nevertheless, this study offers a valuable contribution towards understanding the phenomenon by interviewing occupational therapists with varied experiences.
RECOMMENDATIONS

Recommendations for practice

- That occupational therapists need to challenge their own cultural beliefs and preconceived ideas and reflect on how this impacts their practice in relation to sexual activity.
- That occupational therapists should consider broaching sexual activity with all stroke patients and allowing them to decide if they want it addressed.
- That training should be provided for practising occupational therapists through continued professional development and undergraduate programmes should be considered.
- That sexual activity should be included in multidisciplinary team discussions to ensure it is not neglected in the overall stroke recovery.

Recommendations for research

- That a large quantitative study be considered to investigate the perspectives of stroke patients in Ireland.
- That further research be conducted into the efficacy of occupational therapy intervention for resuming sexual activity following a stroke.
- That a grounded theory study be carried out to develop the concept of sexual activity in occupational therapy.

CONCLUSION

Occupational therapists play a significant role in the rehabilitation of stroke patients through reengagement in meaningful activities. Literature shows that engagement in sexual activity is a concern for people following stroke but is often neglected in stroke rehabilitation. This study, in accordance with its aims, provides insight into the experiences of occupational therapists in addressing sexual activity with people following a stroke. This is the first study of its kind in Ireland and adds to the body of
evidence that suggests there is a gap between occupational therapists’ professional ideology and actual practice. The occupational therapists in this study consider sexual activity to be within the domain of the profession but are adopting a passive role at present, most often referring patients to other health professionals. The cultural norms in Ireland, fear of making a patient uncomfortable and a lack of knowledge and training are reasons that discourage therapists from addressing sexual activity. The most significant finding was that the decision as to whether it is addressed relies heavily on the therapists’ own perceptions rather than on client needs. To date, no one health profession has claimed ownership of this role within stroke rehabilitation. Presumably, many stroke patients in Ireland are being denied intervention to reengage in sexual activity. Sexual activity has been listed as an ADL and is therefore within the remit of occupational therapy practice. This is an important role that occupational therapists can potentially become more involved in. It is envisaged that dissemination of the findings to the participants of this study and in the Irish Journal of Occupational Therapy (IJOT) will encourage new and practicing occupational therapists to reflect on their own attitudes towards addressing sexual activity within practice. Further research is needed to investigate the perspectives of stroke patients in Ireland.
REFERENCES


Appendices

Appendix 1: Review of the literature

Appendix 2: Introduction Letter

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# Appendix 1

## Review of the literature

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Appendix 2

Introduction Letter

10/01/14

Dear Sir/Madam,

I am a final year occupational therapy student at ******** and as part of my degree I have to carry out a research study. The purpose of this study is to explore occupational therapists’ experiences in addressing sexual activity with stroke patients.

I would like to invite you to participate in the study, which would involve being interviewed about your opinions and experiences of addressing sexual activity within your practice. The interviews will take place in February ’14. I have attached an information sheet outlining the study and a consent form. If you would like to participate in the study please read the information sheet, sign the consent form and return it to me in the pre-stamped envelope.

Thank you for taking the time to read this letter. Should you have any queries please feel free to contact me at 086******* or email ******** I look forward to hearing from you.

Yours faithfully,

Signed: ______________________

4th year occupational therapy student
Appendix 3

Information Sheet

Purpose of the study: As part of the requirements for the occupational therapy degree at ****, I have the opportunity to carry out a research study. The purpose of the study is to explore occupational therapists’ experiences of addressing sexual activity with stroke patients. The study aims to gain a deeper understanding of occupational therapists opinions, experiences and roles in addressing sexual activity.

What will the study involve? The study will involve each participant to take part in an individual interview. The interviews will last for approximately one hour and will take place at the participant’s place of work. The interviews will be audio-recorded.

Why have you been asked to take part? You have been asked to participate in the study because you are an occupational therapist working in stroke rehabilitation.

Do you have to take part? No, participation is voluntary but your agreement to do so would be greatly appreciated. You have the option to withdraw from the study at any time, even if you agree to participate.

Will your participation in the study be kept confidential? Yes, I will ensure that no identifying information will appear in the thesis. Pseudonyms will be used throughout. Any extracts from what you say that are quoted in the thesis will be entirely anonymous.

What will happen to the information you give? The information you give will be kept confidential for the duration of the study. On completion of the thesis, it will be retained for a further 6 months and then destroyed.

What will happen to the results? The results will be presented in a thesis. My research supervisor, a second marker and the external examiner will see them. Other occupational therapy students may access my thesis. The study may be published in an academic journal.

What are the possible disadvantages of taking part? I do not anticipate any negative consequences for you in taking part.

Who has reviewed this study? The study has been approved by the *****

Any further queries? If you need any further information you can contact me or my research supervisor:

**** Tel: 086******
**** (supervisor) Tel: 021******.
Appendix 4

Question Guide

1. What do you believe the concept of sexual activity to be about within occupational therapy?

Probes: What makes you think that? Is it a term you are sure about?

2. What are your thoughts on addressing sexual activity as an occupational therapist with stroke patients?

Probes: Can you tell me more? What would make you think that?

3. Can you tell me about your experience of addressing sexual activity with stroke patients?

Probes: How did you feel?

4. Can you tell me your opinion on the role of the occupational therapist in addressing sexual activity with stroke patients?

Probes: Can you elaborate?

5. What would encourage you to address sexual activity with stroke patients?

Probes: Can you tell me more?

6. What would discourage you to address sexual activity with stroke patients?

Probes: How do you think you could overcome this?
Appendix 5

Timeline of study

Sep '13
• Completed research proposal

Dec '13
• Ethical approval

Dec - Jan '14
• Recruitment of participants

Jan '14
• Pilot study

Feb - Mar '14
• Data collection & Data analysis

Apr '14
• Writing up of study

May '14
• Submission of research paper & poster presentation

Jun - Jul '14
• Dissemination of findings
Appendix 6
Sample Coded Transcripts

Siobhan

R: What are your general thoughts on OT’s addressing sexual activity with stroke patients?

P: Ya, like I definitely think it’s kind of an important role and kind of not just around like sexual act kind of a person’s perception of themselves and like roles within relationship ahm…I do think it is a big area. I think its something that we could play a big role I don’t think we necessarily do at the moment. It’s not something that you know would form like a specific part of our framework you know when we are working in practice here. Its kinds of something that’s kind of…It’s addressed in more subtle ways and then there’s the sexual health nurse and it’s passed on that way but that again is just passing the book not addressing what can be a huge area for people. I think it’s important I would like to know more. Ahm…so ya.

R: What are your thoughts on it being an OT role?

P: Ahm…I suppose you know we…within our role here we are working with patients kind of for a long course we get to really know them how they are getting on with their ADL’s their overall function with functioning we look at self-care, productivity and leisure and like you know we do have the expertise analysing activity performance and knowing the impact of disability on ability to perform ADL’s. I do think it’s an area we can look at getting more involved in. I suppose the nurse I haven’t actually worked too much with Pauline it’s very much been a thing of making a referral and then she’ll go and do the work, we don’t get much feedback on it. Ya, I suppose it’s ya an area that’s maybe a little bit neglected. I think as OT’s we do have the you know, we already have a lot of the background information on it and kind of the assessment skill so I think it’s something that we could look to take more of a role in.
Orla

R: What would you do as an OT if somebody asked for advice on his or her sexual activity?

P: So we have a sexual health nurse here who addresses those issues specifically so I would usually refer to her. If they had any specific questions that I felt capable of answering than I’d be quite happy to do that. It’s not something that comes up too often. The whole physiology of it. It’s beyond my scope and what you know…if there’s difficulties around sexual function what the alternatives are. There’s a whole range of information out there and research out there and different positions to make it easier for different tightness of muscles and I just because…I haven’t spent time doing that training I wouldn’t be able to answer the question coherently.

R: Do you think it’s within the role of OT?

P: The problem is, everything’s potentially within the role of the OT and yes OT certainly have the skills to be able to do the activity analysis and do the analysis of the person’s physical functioning and kind of figure out where the match between the two is to enable somebody towards that sexual activity and I’d like to think I’d be open to doing that if that were an opportunity that came up. It's not something that I’ve been asked to do and I think I would need the support from a nurse from the physiological side of things to do that properly. I think it has to be a team approach. I think the primary two difficulties for a lot of our patients, there’s physiological and that’s going to be from a nurses point of view you then have the physical and that’s generally muscles tightness perspective and either a physio or an OT could potentially look at that area and then you go into your behavioural and cognitive issues where you have inhibitions and things like that. Or equally the other aspect where you just have no ambition and looking at managing that.
Appendix 7

Consent Form

Study Title: An exploration of occupational therapists’ experiences of addressing sexual activity with stroke patients.

I…………………….agree to participate in ****’s research study.

The purpose of the study has been explained to me in writing. I have been given the opportunity to ask questions about the study. I am participating voluntarily.

I agree to take part in this study, which involves being interviewed. I give permission for my interview with **** to be tape-recorded.

I understand that I can withdraw from the study at any time up to two weeks after the interview without repercussions.

I understand that my anonymity will be respected by disguising my identity in the final research paper.

I understand that disguised extracts from my interview may be quoted in the final paper and in any subsequent publications.

Name of Participant       Signature       Date
_________________________  _______________  ____________

Name of Researcher        Signature       Date
_________________________  _______________  ____________