

Abstract

The purpose of this study was to evaluate, from the perspective of an occupational therapist, what experiences or education created competent health professionals with regard to addressing sexual health concerns and to gather suggestions on how to increase the confidence of therapists about sexual health in the profession as a whole. A qualitative design with a semi-structured interview was used to gather data from two therapists with extensive experience addressing sexual health for people with physical disabilities. Data from the interviews revealed four major categories with subthemes. (1) 'Why Address Sexual Health?': Just Part of OT's Job!, Enhancing Quality of Life, and To Open Communication. (2) 'How to Gain Competence in Sexual Health': Formal Education, Medical Knowledge, and Continued Learning. (3) 'How to Gain Confidence about Sexual Health' with subthemes: Personality and Practice. (4) 'Suggestions for New (or Nervous) Practitioners': PRACTICE! and Find Resources. This study indicates the importance of addressing sexual health concerns for clients, as it can have a great impact on quality of life. The participants in the study suggested achievable ways for occupational therapists to increase their knowledge base and comfort with the topic, so the unique skills of a practitioner can be used to enhance sexual health, as well as other meaningful activities.

Competent and Confident: An Occupational Therapist Perspective on Sexual Health

A person who has experienced a traumatic injury resulting in a permanent physical disability, or one who has a congenital illness or disability should not be thought of as simply *disabled*, but as “a person who has a desire for adequate interpersonal and sexual functions and who happens to have certain disabilities” (Szasz, 1991, p. 562). As sexual activity is an activity of daily living (ADL) and defined in the Occupational Therapy Practice Framework as “engaging in sexual satisfaction” (American Occupational Therapy Association, 2008, p. 631), it falls under all occupational therapists’ scope of practice.

In the past, treatment of sexual concerns was relegated to sexual therapists or other professionals and focused mainly on physical issues, such as erectile dysfunction (Alexander & Alexander, 2007). It should be acknowledged, though, that sexuality contains emotional, social, and developmental aspects (Evans, 1985). It would be interesting to learn if occupational therapists are addressing both the physical issues as well as the emotional and psychological issues to meet the needs of clients. McAlonan (1996) conducted a qualitative study to determine the effectiveness of sexual rehabilitation services for 12 people with spinal cord injuries. She found that although many of the participants reported receiving services of some kind, there were many who reported being unsatisfied with the quality or quantity of the sexual rehabilitation services provided (McAlonan, 1996).

Since the clients were dissatisfied with the services provided, it would be important to determine the occupational therapist perspective on the value and effectiveness of his or her role in sexual health education. Haboubi and Lincoln (2003) surveyed a group of health professionals, including occupational therapists, and found that 90% felt sexual

issues should be addressed during care. In spite of this, 68% reported never initiating a conversation about sexual health concerns. Similarly, Rogers (2007) surveyed only occupational therapists about whether they believed that sexual rehabilitation services were part of their job role, and about how often the therapists initiated a conversation about sexual health. She found that 63% agreed that occupational therapy goals could include sexuality or sexual dysfunction, although the majority of respondents (62%) reported rarely initiating this conversation and 29.3% of therapists reported never initiating this conversation (Rogers, 2007). Thus a majority of occupational therapists are concerned with the importance of the ADL of sexual activity, although a substantial minority has reported that they do not incorporate it into their practice.

The profession of occupational therapy regards a person in a holistic sense, seeks to enable a person to participate in meaningful activities as much as possible, and thus to focus goals on what is important to the client (American Occupational Therapy Association, 2008). When Cole, Chilgren and Rosenberg (1973) questioned people with paraplegia or quadriplegia about the importance of having a satisfactory, active sex life to personal happiness, 70% of males and females with paraplegia agreed or strongly agreed and 50% of males and females with quadriplegia agreed or strongly agreed. Fisher et al. (2002) identified more specific sexual rehabilitation concerns for people with spinal cord injuries: not satisfying a partner, not enough sexual satisfaction, lack of knowledge since the injury, and feeling unattractive because of the injury. An occupational therapist may be able to address some of these concerns relating to sexual activities with specific regard to individual client factors, body functions, activity demands, environmental considerations, as well as psychosocial aspects.

Background

It may not be widely recognized, but people with physical disabilities have the same sexual desires and needs as people without disabilities (McCabe, Taleporos, & Dip, 2003; Moin, Duvdevany, & Mazor, 2009). The U.S. Census Bureau lists over 21 million people living with a physical disability, and for them it can be a very important aspect of their rehabilitation needs (Waldrop & Stern, 2003). McCabe et al. (2003) surveyed people with physical disabilities and people without a disability to determine the relationship between degree of physical disability and levels of sexual esteem, sexual depression, sexual satisfaction and frequency of sexual behavior. The results indicated that people with severe physical disability had significantly lower levels of mutual sexual activity, solo sexual activity, sexual esteem and self-perceived attractiveness to others compared to those with more mild physical disabilities or people without disability.

Moin et al. (2009) found similar results surveying 134 women, 70 with disabilities and 64 without, on three questionnaires: Sexuality Scale, Body Image Scale, and Quality of Life Questionnaire. The results indicated that women with physical disabilities scored significantly lower on items like body image, sexual self-esteem, sexual satisfaction and life satisfaction. This sub-group, however, expressed the same sexual needs and desires as women without a physical disability. In a more specific population, people with amputations, Walters and Williamson (1998) found that sexual satisfaction was associated with a higher quality of life. Those who were experiencing pain related to the amputation reported lower sexual satisfaction and lower quality of life. The authors suggested that "...counseling-or, at a minimum, opening the door for discussion-about sexuality in the

rehabilitation process may moderate patients' sexuality-based anxieties which, in turn, can improve their quality of life." (Walters & Williamson, 1998, p. 112).

Leibowitz (2005) found that women with spinal cord injuries also supported the idea of a health professional broaching the topic of sexual health, since some women reported avoiding the topic if no attention was given to it. Of the 24 women surveyed about their counseling experiences and sexual concerns after injury, there were some common themes and recommendations. The respondents stressed the importance of determining the individual goals of the client in regards to sexual rehabilitation, or education, and that the timing of this information played a large role in the woman's satisfaction with her sexual rehabilitation services.

Appropriate timing for sexual health services was supported by Fisher et al. (2002). They surveyed 40 people with spinal cord injuries (32 male and 8 female) and revealed that during the time from inpatient rehabilitation discharge to 6 months post-discharge, participants had an increased interest in sexual information and counseling. The investigators suggested that at this point the respondents have a better awareness of how their injury may affect their sexuality, and what their new or different interests and goals may be.

Several studies have outlined the main sexual concerns of people with disabilities. Phelps, Albo, Dunn and Joseph (2001) surveyed 482 male veterans with spinal cord injuries about behaviors, functioning, needs and satisfaction related to sexual activities. The results showed partner satisfaction, sexual desire, relationship satisfaction and sexual repertoire significantly correlated to the Sexual Behavior, Enjoyment and Satisfaction scale. The items that were purely physical, such as erectile function and genital sensation were not

significantly related to sexual behavior and satisfaction (Phelps et al., 2001). This suggests that sexual health education needs to cover not only the physical aspects of disability, but should also encompass the emotional and psychological aspects. Sakellariou and Sawada (2006) discovered emotional and psychological themes in the sexual adjustment of Greek males with spinal cord injury as well. The themes for positive sexual adjustment according to the respondents' testimony emerged as changes in perspective, enjoyment and barriers. The barriers were mostly from societal views that men should be independent and the perception that people with disabilities cannot be sexual. It was also important for the men to change the definition of sexuality in general and redefine the image of themselves to facilitate a healthy adjustment after injury. Last, it became important to simply learn to enjoy sexual activities, even if they were different from the activities done prior to the injury.

It is clear that sexual health education should be a part of rehabilitation services and cover both physiological concerns and emotional or psychological concerns of the individual. The interviews conducted by McAlonan (1996) found many people with SCI feeling unsatisfied with the services provided regarding sexual rehabilitation. One frustration was with insufficient information provided and another was with the manner in which the information was presented. A suggestion from the individuals interviewed was to use one-on-one counseling as the initial step, since sexual health may be too private a matter for some people to share with a group, however, a progression to group settings should be available for those who prefer that approach. The health care professional providing the information can also have a large influence on the person's level of satisfaction with the sexual health education. The respondents noted the personality, body

language, and attitudes as factors that contributed to level of satisfaction and preferred a “direct, open style of communication” (McAlonan, 1996, p. 829) from the provider.

Couldrick (1998) believed that a key component of occupational therapy is holism, and “holism unifies all facets of a person including his or her sexuality and its expression” (p. 495). Occupational therapists have the ability to analyze dysfunction in occupation and to select treatment techniques or adapt activities as required to support performance. Therefore, occupational therapists may be the health care professional providing information on sexual health, although this is not always true. Novak and Mitchell (1988) surveyed rehabilitation nurses and occupational therapists to determine how sexuality counseling was provided in practice. There was no significant difference in the priority of sexuality counseling in the total rehabilitation of a patient between the professions, although rehabilitation nurses reported a greater involvement in sexuality counseling than occupational therapists ($X^2 [1] = 6.20, p = .01$). A potential reason for the difference may be that nurses had received more training in sexuality counseling than occupational therapists.

Haboubi and Lincoln (2003) similarly surveyed a group of professionals ($N = 813$) including nurses, doctors, physiotherapists and occupational therapists about discussing sexual issues with patients. Of the respondents, 90% agreed that sexual issues should be addressed as part of holistic care, however, only 6% began a discussion on a frequent basis, 26% did a few times, and 68% reported never initiating a discussion about sexual issues. The respondents nominated nurses and doctors to cover sexual concerns, while occupational therapists and physiotherapists were nominated the least. The therapists were less likely than other professions to have previous training, feel comfortable, or be

prepared to offer advice to patients or to encourage open discussions (Haboubi & Lincoln, 2003). This lack of involvement from the occupational therapists could impact the comprehensiveness of the rehabilitation for the individual. Occupational therapists understand the importance of participation in meaningful activities, how the emotional state can impact performance, and have skills in activity analysis, which combine for a unique perspective when addressing individual goals concerning sexual activity.

Regardless of the level of training, occupational therapists should be proactive in initiating a discussion about general sexual health with clients to determine the presence of any concerns by the individual. There is a useful model to aid in determining the needs of the client and the level of skill and comfort required by the professional involved. The PLISSIT model developed by Annon (1976) provides four levels of approach to treatment concerns: Permission, Limited Instruction, Specific Suggestion and Intensive Therapy (Esmail, Esmail, & Munro, 2001; Madorsky & Dixon, 1983). The first three levels are appropriate levels of intervention for most health care professionals (Esmail et al., 2001; Madorsky & Dixon, 1983). At a minimum it is recommended that the therapist be prepared with general information and should have a means of obtaining more specific information to avoid frustration or disappointment in the client due to insufficient information. The therapist being open to acknowledging the person with disabilities as a sexual being may give the client the confidence needed to disclose any personal concern.

To determine if education increased the competence and comfort of health professionals, Post, Gianotten, Heijen, Hille Ris Lambers, & Willem (2008) provided a discipline specific sexological training for physicians, nurses, psychologists, social workers, physical therapists, occupational therapists and speech/language therapists. A pre-test

was used to measure what the perceived competence was regarding sexual rehabilitation among the different professions and then a post-test was administered after the education intervention (ranging from 6 to 9 hours) to ascertain if training led to improved competence. Of the participants, 81.7% felt discussing sexual concerns was part of their profession, with physicians rated the highest (99.5%), physical therapists the lowest (60.5%) and occupational therapists in the middle (76.9%). The pre-test revealed that occupational therapists rated their sexological competence significantly lower than other professions rated theirs. At follow-up, however, the occupational therapists and physicians showed most improvement in competence level. This illustrates that even a small number of hours of specific training can increase perceived competence and can better prepare occupational therapists to address the sexual concerns of clients.

As the questions and concerns for individuals can vary to a great degree, it is unlikely that written materials or information gained from a website would completely satisfy those with physical disabilities looking to increase both their sexual and life satisfaction. It may be beneficial to include an occupational therapist in the sexual health education to address the unique concerns of the person, focusing on individual strengths, abilities and desired activities. Addressing sexuality concerns falls within the scope of practice of an occupational therapist, so it is important to encourage a profession that is skilled in rehabilitation to address goals regarding sexual health. Therefore, the purpose of this study is to evaluate, from the perspective of an occupational therapist, what experiences or education created competent health professionals with regard to addressing sexual health concerns and to gather suggestions on how to increase the confidence of therapists about sexual health in the profession as a whole.

Method

Research Design

One description of a qualitative design states that the “approach to interpreting and analyzing data has to do with interpreting words, not numbers” (Dillaway, Lysack, & Luborsky, 2006, p. 372). That is why a qualitative design was used in this study in order to document the experiences and insight of occupational therapists on providing sexual health education to people with physical disabilities. Specifically, a grounded theory approach was implemented, since the researcher did not set out to confirm a theory, but rather found the information that was relevant by allowing it to emerge throughout the data collection and analysis processes (Strauss & Corbin, 1990). Survey evidence has suggested that occupational therapists believe sexual health should be addressed as part of holistic care, but have less involvement than other professions (Haboubi & Lincoln, 2003; Novak & Mitchell, 1988). Therefore, in order to develop a profile of treatment practice from therapists with ample experience, a qualitative interview may give insights that surveys could not.

Participants

The population of interest for the project was practicing occupational therapists in the U. S. who have worked with people with physical disabilities and have addressed sexual health in their treatment. Specifically, the inclusion criteria consisted of: experience working as an occupational therapist with people with physical disabilities, incorporation of some form of sexual health education into practice, a belief of having knowledge of sexual health, confidence in treatment delivery, and a willingness to discuss personal experiences. Also necessary was a willingness to participate in one 60-75 minute interview

and a subsequent interview of 30-45 minutes, which included signing a consent form and permission to audiotape the interviews.

Two participants were identified through network sampling of occupational therapists in the Pacific Northwest utilizing occupational therapy faculty recommendations and suggestions (Dickerson, 2006). Given the time and resources available for the project, this number was deemed sufficient to obtain emergent themes from the data. In order to maintain confidentiality, the two participants, one female and one male, provided a pseudonym for use in the study.

Jennifer is a White female in her 40's. She has over 20 years of experience working as an occupational therapist, and has worked for over ten years in a home health and hospice setting. Jennifer also has experience working in acute care, rehabilitation, a skilled nursing facility and an outpatient clinic. She reported that for all her years of practice, addressing sexual health was part of her employment. Toby is a White male under the age of 30 years old. He has been practicing for less than five years, and has had all of his experience in in-patient rehabilitation, where sexual health education has been part of his work.

Procedures

Prior to the start of the study, the author underwent a pilot interview with a university professor experienced in qualitative research and treatment of people with physical disabilities, while another research faculty member observed. Demographic questions and note-taking strategies were revised following the pilot interview based on feedback from the involved parties. The study began following approval from the university Institutional Review Board with participant recruitment. The participants

selected locations for the initial and follow-up sessions, and signed a consent form prior to the start of the interviews. All interviews were documented with a digital audio recorder and field notes were taken by the researcher.

The initial interviews began with a grand tour question, inquiring about the therapist's experience in addressing sexual health concerns for people with physical disabilities. Some specific follow-up questions were used to focus the interview on the means by which the therapist gained knowledge about sexual health and rehabilitation and at what point he or she felt confident about providing sexual health education (see Appendix). The initial interviews lasted 65 minutes. Follow-up interviews lasted approximately 40 minutes, which included member checking for accuracy of the preliminary interpretation of the data and additional clarifying questions.

Data Analysis

The data for the study consisted of the initial interviews and follow-up interviews with both participants. The audio recorded interviews were transcribed by a professional transcriptionist and checked for accuracy by the author. During the interviews, the researcher took field notes to record responses and to document observations and personal reactions to the conversation topics. The data analysis began with open coding, to identify concepts as they emerged from the data. After much time with the interview transcripts and field notes, a combination of a priori and a posteriori categories were used to resort the data. A final classification of concepts from the data to connect or distinguish the categories was made which allowed for firm development of themes (Strauss & Corbin, 1990).

Several measures were taken to enhance the credibility of the study. The initial interview format, mostly being an open conversation guided by the participants' comments, allowed for an accurate representation of the person and portrayal of his or her experience. A research faculty member with significant experience in qualitative design reviewed a sizeable sample of the initial coding for accuracy. During the follow-up interview, preliminary findings and interpretations were discussed with the participants.

Results

After repeatedly reading interview transcripts, examining observation notes and obtaining feedback from an experienced qualitative researcher with an extensive background in sexual health, the author decided the data could be assigned to four main categories, with subthemes. The first category is 'Why Address Sexual Health?' with the subthemes: Just Part of OT's Job!, Enhancing Quality of Life, and To Open Communication. The second category is 'How to Gain Competence in Sexual Health' with the subthemes: Formal Education, Medical Knowledge, and Continued Learning. Third, the category is 'How to Gain Confidence about Sexual Health' with subthemes: Personality and Practice. The fourth category is 'Suggestions for New (or Nervous) Practitioners' with the subthemes: PRACTICE! and Find Resources.

Why Address Sexual Health?

Just Part of OT's Job! Both participants reported that for each client, the goal of occupational therapy treatment is to work on activities that are meaningful to that individual; and for many of their clients sexual activity is meaningful. Jennifer explained the importance of including sexual health as a means "to be a full service OT doing all that OT has to offer." She further explained, "sex is just, it truly is just another activity... it's

intimate, sure – like toileting is intimate, and bathing is intimate and dressing is intimate and feeding is intimate. But what does an OT do that’s not intimate?” Jennifer would introduce this domain of her practice to her clients by “presenting it like it’s just the facts...this is just part of what I do for a living.”

Toby indicated that sexual activity “falls in the OT framework as an ADL” but that does not make it inherently easy to educate a client. He stated,

Our society is set up to, like, make sex more of a taboo topic. So, as a provider I am not going to change that. But I think the reality is as a healthcare provider, it is our job to provide patients with information.

He reported similar sentiments to those of Jennifer, to treat sexuality health education similar to other ADLs;

Toileting is not really glamorous and it’s really personal. But it’s really important. If you don’t go to the bathroom, you have a number of health complications and you are at risk for a lot of bowel impactions...so many complications. I think some might say that sex is less important and maybe to an extent it is, but are there risks? Yes. There are risks. And I think if there are health risks then it is our job to disseminate that.

The participants both described sharing sexual health information as a routine task during treatment while employed as an occupational therapist, and did not differentiate it from treatment activities addressing other ADLs.

Enhancing Quality of Life. In discussions regarding the provision of sexual health education for clients, the informants emphasized their focus on improving client’s quality of life by addressing physical and psychosocial needs. Jennifer said, “And talk about quality of life – that can make it or break it. And people can get depressed if they don’t have it. And their partners can get depressed. And their partners can get resentful.” She remembered a time when a client told her “one of the things I really miss is being able to have sex.” Her response was, “What is it that is the problem you feel like you can’t have sex? ...if it’s a

fulfilling activity for you and it improves your quality of life, then it should still be an activity that you can engage in.”

The occupational therapist or other health care professional may be the person that assists a client to know that sexual activity is still an option. Of his clients, Toby said, “they are people first...how would it be for them to not be seen as sexual beings” and continued, “if you don’t have context for that...then you think my sex life is over. And it doesn’t have to be.” Toby spoke to the challenge of reframing the situation for his clients,

...I think that makes it hard especially for people that are injured...because I think they have this sexual identity that was them as an able-bodied person, and now not as an able-bodied person, they don’t have a context for how they can even consider going back to sex.

To introduce a new context for his clients, Toby tries “finding a balance of realism and just optimism.” Jennifer also helped find a context for her clients, since she “knew that if they were asking there was a reason for it. And it was me being able to make a contribution to their quality of life again.”

To Open Communication. Being able to determine if a person would be interested in sexual health education is the first step in addressing these concerns. The first conversation was deemed one of the most important steps in the education process for each individual client. Toby commented, “in order to make that person feel safe enough to say yes it is, we have to be able to have that interview in a respectful and open way that makes the person feel comfortable.” Jennifer tries to introduce the information the same to each client “as an option as part of the treatment plan.” She elaborated,

If you have questions about this stuff, that is part of what I do – you can ask me about that. And if they don’t want to ask, they don’t ask me. And if they want to ask me, they ask me. So, they are interested in the topic. So – and if – as long as I am presenting comfortable appearance, then they are comfortable.

She also mentioned talking about sexual health in the early phase of treatment, so “each subsequent visit they are going to ask you one more detail, and one more detail.”

Beyond the first conversation, to maintain a positive environment, both practitioners concentrated on really developing a healthy relationship with their clients, in ways that were authentic to each of them. Toby described trying to “meet people where they are” but also mentioned that it “is a fine line because you are not their friend – you are a health care provider” and last mentioned that “it’s a balancing act of kind of really building that friendship kind of relationship with people so that you can build trust, build an open space” for continued conversation and education. He stressed trying to open the conversation between the health care provider and the client as a start, so that the open communication would then infiltrate the personal life outside of a formal setting. From the client perspective his example was,

I have to be able to figure out what is not working for me. So, I have to think about what function I have in my arms and how I am going to transfer and, you know, what sensation I have and what I am looking for and what I miss from sex.

He wanted to empower people with disabilities to do some self-discovery to make educated decisions for their personal lives beyond a rehabilitation setting. Toby also thought of other professionals, and how each person needs to know their own beliefs and how they are communicating, verbally and non-verbally with each client and the impact that has on open communication and the education. An example,

I am comfortable having that conversation with pretty much anybody that wants to talk to me about their sex life. Whereas, if people come into these conversations with a lot of judgment about any of those people, I think that people can pick up on that. You don’t have to say something hateful to make someone feel uncomfortable.

How to Gain Competence in Sexual Health

Both participants in the study had ample experience working with people with physical disabilities, however, each had a varied background of education, work setting experience, means of continued learning, specific medical knowledge and concern for acquiring knowledge to provide the best possible care for their clients.

Formal Education. Prior to the start of his graduate studies in occupational therapy, Toby took a disabilities studies course during his undergraduate career, which introduced him to a theater group that tried to normalize sex and disability. He remembered a short act and the message was, “we have disabilities and we have sex (...) and just being sexy.” While in graduate school, sexual health was covered as a subtopic during a lecture on spinal cord injuries, but he indicated it was minimal. Jennifer earned a bachelor’s degree in occupational therapy, and it was in her school years that she first thought about sexuality and people with physical disabilities. She remembered, “they showed us a video on how people with spinal cord injuries could be sexually active (...) I was a little bit stunned by it because it felt like watching pornography and I had never seen anything like that before.” Both participants had an introduction to the topic during their years in education, and although the time was limited, they reported it feeling like a good intention to provide a context for people with disabilities to be seen as sexual beings.

Medical Knowledge. The participants have worked in distinctive settings, and reported understanding the specific conditions of the clients in that setting presented as a valuable way to begin a discussion about sexual health. Jennifer explained,

It’s so easy to talk about hip precautions and positions and cardiac precautions and sternal precautions. And if you are starting to feel short of breath, stop and rest – you know? And this is what your pulse is supposed to be when you exercise – that’s what your pulse is supposed to be during sex,

too. Don't go higher than that, you know? If you need to, stop and rest. Or be on your back and let the partner do the work.

Additionally, Toby explained the importance of putting medical information and vocabulary used by physicians, or on websites, or other materials used into vocabulary that suits the individual as a means of educating a client. He then emphasizes the explanation should relate to the client's personal situation, and "apply the education...to everybody to what we know about that person's sensation and function and things like that." He elaborated,

So being able to kind of review information to make it more understandable is important. But I think also saying, okay, so what they are saying is it's kind of like a, you know, a reflex is how this erection happens. And so you can – in your case you actually – I've noticed that you still have those erections when someone touches your catheter or whatever else. So, that's a good sign that maybe you can have these erections. And being able to kind of really apply it to their specific situation.

Adequate medical knowledge provided a solid foundation for both participants to be competent health care professionals in general.

Continued Learning. To enhance his base medical knowledge, and of his own volition, Toby attended two conferences on sexual health. He commented that clients' "are going to research everything" so this may be a good way to remain current on sexual health information. One of the conferences was presented by a medical doctor and the other by an occupational therapist. The range of information was "what research shows about this vibrator for ejaculation" to "medications for sexual function" and "positioning equipment and other kind of issues that [he] thinks are more practical and functional."

To share some of his acquired knowledge and professional interests on sexual health, Toby has been part of projects outside of work. He has developed a presentation on sexual positioning equipment and adaptive devices, including a Power Point and a written

booklet, for people with disabilities as well as other health professionals. Toby shares these resources so if other therapists don't have a lot of knowledge with this topic "they don't have to feel like they have to talk a whole lot in depth about it, but they can demo it." It gives the client the information he or she may want, and the therapist information he or she may continue to use in a less intimidating format.

Jennifer also found ways to continue learning about sexual health and a means to share her knowledge. Her personal education was less formal than a conference setting to disseminate information, but she praised the skill and style of her mentor, starting with her experience in Level II Fieldwork. When providing co-treatment with her supervisor, she reported she simply started, "by listening to her – like observing her doing a treatment session and listening to what she said. And I was a sponge and I just absorbed everything that she said. And everything that she did."

To share the knowledge Jennifer acquired, she took on the task of creating some written materials for her organization. The goal was to include information on sexual health in a more standard manner, so the topic received similar emphasis as other ADLs received,

...this booklet that we made that was like all the drawings of people putting on socks using their sock aide and drawings of sitting in the proper positions depending on which approach you had had – anterior or posterior or whatever – and one of the pages was sexual health and sexual activity after a total joint replacement. And we put it in there because we wanted it to be just matter of fact, just part of the plan.

For both participants, the combination of formal and informal educational opportunities, a solid base of medical knowledge pertinent to the population at the work setting, and experience with additional projects related to sexuality health added to their competence with addressing sexual health concerns for their clients.

How to Gain Confidence about Sexual Health

Personality. Toby did not have much of a transition to being comfortable with sexual health for people with disabilities. Within five minutes of the start of the initial interview Toby said, “I think sex is such an important part of everyone’s life – most everyone.” And, he added shortly after, “I think sexual health is essential to have a good quality of life and I think in society we don’t kind of see people with disabilities as being sexual beings.” With a solid belief that sexual health is important, it may be easier to include in treatment. However, in addition to this belief, Toby also has strong communication skills. He credits “other avenues” rather than sexual health education as a means to better communication skills. He indicated,

I think that my advocacy and my interest in advocating for challenging issues kind of started because of my being a minority and advocating for issues that are important to me in society and just personally. So, I think – I really feel like doing education for sexual health is a way to not only advocate for an area of need for each individual, but I feel like also is a way to be a social advocate...to kind of help change society’s views of people with disabilities on an individual level.

Jennifer also believes that sexual health is important, “because it is an activity of daily living” but also had some reservations initially. She said, “I interpret it as a potentially anxiety-producing conversation for them. And at first it was anxiety producing for me.” To deal with some of the anxiety, she said she “just kind of gritted her teeth and did it” and also mentioned it was good that she “can keep a really straight face.” Jennifer knew the importance of putting aside her personal emotional responses to address sexual health concerns.

Practice. For Jennifer, she only had to hide her emotions temporarily before she truly became comfortable. She received some positive feedback during her initial sessions,

“it felt like a master experience that made me feel a little more confident going into the next one. And then the next one after that was successful.” Now she reports with much confidence,

...talking about sexuality with my patients is just part of my repertoire, it’s something I can do, and I just dealt with the mortifying, humiliating feeling initially about it, saw that they responded positively to it – or when they were asking questions and I was providing appropriate answers and they had such good reactions to that – then it took some of the fear away.

Jennifer also admitted that as her personal life developed, her confidence improved. Initially, she was “speaking theoretically” but later she reported “after I became a person whose sexuality was getting more fully formed...I understood it at a whole other level and then I was more comfortable.”

Toby may have also gained additional confidence through practice. Some of his clients were given the option to discuss their sexual health concerns with a rehabilitation psychologist, but “were like telling [him] that they didn’t want to talk to rehab psych about it. Because they already had a relationship with [him].” Toby had an increase in experience due to client preference for him to address the issue, as well as from colleague referral. He reported,

I have actually found that there are a number of clinicians regardless of discipline that don’t really enjoy talking about sex...People are really willing to just be like, no, go for it...So, I find that people when given the opportunity to have an out typically take it.

Having the willingness to discuss sexual health, even if it initially makes a person uncomfortable, may be the best first step to gaining confidence in addressing sexual health concerns for people with disabilities.

Suggestions for New (or Nervous) Practitioners

The order of the following themes is representative of the order the suggestions were articulated by both the participants.

PRACTICE! The overwhelming recommendation from the participants for new practitioners, or experienced practitioners who may have avoided sexual health education, is to practice. Jennifer suggested to students, “just practice talking to each other about it...it’s just another clinical skill to be able to say breasts and penis and vagina and whatever.” She continued her thought on practice,

You do anything – even if it’s something shocking or embarrassing – if you do it long enough you end up comfortable with it...and eventually you accommodate to it and it just becomes normal. Part of your repertoire of things you can do.

Toby added that as occupational therapists he “didn’t feel like we should be struggling to keep a straight face when we are talking about sex.” On top of just practicing with a friend, partner or colleague, it is possible to practice the presentation to the client. He said,

...sometimes it is just easier to say look, people aren’t comfortable talking about this...I know that you are not used to talk about this with, like, strangers or health professionals – you know, I don’t go to my doctor and talk about my sex life all the time either. And you kind of need to be able to talk about it now.

Find Resources. The resources recommended by the participants were a way to help practitioners start the conversation and utilize resources to guide the subsequent treatment. Toby admitted, “I was doing very minimal education initially. And really like by the book. Like literally let’s look at the book.” He added, “I think half of the importance I think of education is just starting the conversation and less about information.” The participants utilized different handouts and websites during their treatments, but both of them watched, learned from or incorporated, the movie *Sexuality Reborn*. The movie

discusses and demonstrates some options for sexual activities for people with spinal cord injuries and one person with spina bifida. Toby mentioned that if “you are an able-bodied person that’s an OT and you don’t know anything about people with disabilities having sex, it’s really hard to really discuss how that is going to work.” Jennifer suggested another film, “if you want to hear disabled people talk about sex, watch *Murderball* and you will get desensitized to it.” She recommended the movie “on so many levels because looking at their wheelchairs, looking at their social interactions with each other and with able-bodied people – looking at people’s reactions to what they do” to just learn. Other than the movies, Toby recommended, “doing some sort of research whatever that means to you.” He has spent time “looking at sex toys and trying to look at sex furniture and trying to see what is out there” since clients will look things up, and he wants to be able to offer medically-sound options.

Discussion

Why Address Sexual Health?

In 1988, Novak and Mitchell surveyed rehabilitation nurses and occupational therapists and found that the nurses reported greater involvement in sexuality counseling than the occupational therapists. In 2012, the results of this study suggest that occupational therapists may be taking a larger role in sexual health education. Both participants indicated that this type of service falls within the domain of occupational therapy and is officially categorized in the Occupational Therapy Practice Framework. Sexual Activity is actually listed as an ADL and appears again under social participation (American Occupational Therapy Association, 2008).

In addition to the American Occupational Therapy Association's confirmation that it is an important topic for practitioners to address, it also impacts the quality of life for individual clients. Walters and Williamson (1998) found that moderating sexuality-based anxieties for people with amputations could improve quality of life, while Cole et al. (1973) found that having a satisfactory, active sex life for people with paraplegia or quadriplegia impacted client happiness. The participants in the current study supported the previous research by echoing the importance of addressing the physical and psychosocial needs of clients with physical disabilities to enhance quality of life. For a person with an acquired disability, one participant said the emphasis is "just kind of shifting their frame of reference for themselves and introducing the ideas of them being sexual beings with and without disabilities."

The results of this study indicate the importance of opening communication with a client to support sexual health. While there is literature that indicates occupational therapists believe that sexual health is an important part of treatment and falls within the practice domain, Haboubi and Lincoln (2003) reported 68% of respondents never initiated a conversation about sexuality. Rogers (2007) had similar results and found almost 90% of respondents reported rarely or never initiating a conversation about sexual health. One of the current participants said of the importance of discussing sexual health that "the education is just starting the conversation and less about information."

While literature supports that most occupational therapists believe discussing sexual health is an important component to treatment, the literature does not indicate that initiating this conversation is an easy task. The participants in the current study had unique communication styles. They recommended enhancing personal communication

skills as one way to improve communication within a professional setting, so as to be able to open the first conversation. One participant pondered,

I haven't really figured out how to make people more comfortable talking about it, but in all reality, there are a lot of people that never feel comfortable talking about their own sex life...I think that's a good way to practice talking about sex with other people is are you comfortable talking about your own sex life?

The recommendation was not that professionals must talk about their personal lives with clients, but rather to explore what makes them uncomfortable and determine if that is impacting their verbal or non-verbal communication skills, and if that is a reason for avoiding sexual health education. The other participant mentioned it was an easier topic when it was related to a client and said, "fortunately I never had to talk about my own sexuality – it was always theirs." Regardless of whether a practitioner would be willing to explore personal communication habits, the participants stressed the need for starting the conversation in a respectful manner to provide the option of the service if sexuality played a meaningful role for the individual. Leibowitz (2005) found women with SCI supported the idea of the practitioner beginning the conversation. By initiating the conversation, it decreases the odds that the topic gets missed, which could also decrease the odds of a missed opportunity to improve the quality of life for someone.

How to Gain Competence in Sexual Health

The results of this study indicate that there is no linear path to being a competent health care provider with confidence in addressing sexual health. There were, however, similar features in the backgrounds of the participants including formal education, a solid foundation of medical knowledge pertinent to the population served, and an effort to continue learning, in a manner that suits the practitioner. Novak and Mitchell (1988) found

rehabilitation nurses more involved in sexuality counseling than occupational therapists, and one reason for the difference may have been that the nurses had received more training. However, Post et al. (2008) demonstrated that even a small number of hours dedicated to sexual health education for health care professionals increased the competence of occupational therapists to address client concerns. Both participants indicated that not much time was spent on sexual health in their occupational therapy studies. Education programs provide a brief introduction to many topics to students in a short time. Professional entry-level education may only be a means to begin building a knowledge base. One participant sought out continuing education specifically on sexual health, and the other depended more on observations of more experienced practitioners. Either avenue seemed to provide a positive contribution to their knowledge base.

McAlonan (1996) found many people with SCI unsatisfied with the sexual rehabilitation services they received. One of the reasons was that insufficient information was being provided. This finding suggests that having an accurate medical understanding of the client population would help an occupational therapist more adequately answer questions regarding sexuality. One of the participant's self-descriptions was "the OT who can't stop task-analyzing everything" and the other concurred with "to make really good adaptive equipment, you have to really be able to break down the task and what is limiting someone's participation in the task." A good understanding of medical conditions and the ability to perform a task analysis may help the practitioner feel more prepared to offer sufficient information, even if the person is less experienced with sexual health education. The population of clients, the level of education incorporated into occupational therapy

curricula and the level of basic medical knowledge may help guide a health care professional to the appropriate means to gain more insight into sexual health information.

How to Gain Confidence about Sexual Health

The profession of occupational therapy may attract people for a variety of reasons. Practitioners can vary greatly in professional interests, personality and therapeutic style during treatment. Toby and Jennifer represent a little of the likely variation throughout the profession, in that the two did not have the same challenges to building confidence in their individual experiences with sexual health education. However, each participant believed that if sexual activities were meaningful to a client prior to temporary or permanent disability, then sexual activities should continue to be meaningful. Moin et al. (2009) surveyed women with and without disabilities and found the sub-group of women with disabilities expressed the same sexual desires and needs as those without, confirming the participants' belief. For clients, like the women in the Moin et al. (2009) study, one participant used an "identity as a minority" to create a role in the work setting to advocate for people newly injured, that "helps advocate for the sense of identity with and without that disability identity – with their family and friends, and how to navigate that new role." To provide sexual health education thus seemed natural.

However, for the other participant, as for many occupational therapists, providing sexual health education may not feel natural. The participant added that a little practice is key,

Like singing in public or like public speaking, it can be really uncomfortable to do it but you do enough of it and eventually you accommodate to it and it just becomes normal. Part of your repertoire of things you can do.

Along with practice, finding resources to guide your education on sexual health may also help increase confidence, since the materials may help guide the treatment session. At one site, “people [occupational therapists] have been really enjoying using that booklet, because they can say look – like it doesn’t have to be something that they know a whole lot about.”

For the variety of personalities in the occupational therapy profession, the participants provided tangible ways to increase confidence about sexual health, whether a novice or expert practitioner. With new resources to guide a therapist, a little practice could have a positive impact on confidence during treatment, increasing the likelihood that the information is reaching the clients.

Expertise in Sexual Health

Both participants showed a strong interest in sexual health for people with physical disabilities. However, when asked if their interest and knowledge made them consider themselves an expert in this area of practice, each of them were quick to say no. The informants thought that if they were addressing sexual health concerns, that most, or all, of their colleagues were as well, so they considered their knowledge unremarkable.

The two participants were asked to describe an expert, regardless of the subject, and list some of the characteristics or qualities that person would have. They described a knowledgeable person, one that was resourceful about finding information or answers and had a willingness to share or contribute back the knowledge they had gained. The other descriptors used were a “skilled practitioner” and one who has “a passion for the subject.” The author paraphrased the definitions, and described parallel personal skills or qualities the participant had regarding sexual health education, and then asked again if they

sounded like an expert in the area of practice. Toby did acknowledge that since he sought out more resources about sexual health than many of his peers, “it sets [him] apart from them even though they have more years of practice experience.”

The participants in the study were knowledgeable, resourceful and freely shared their information. By their own definitions they may be experts in sexual health education for people with physical disabilities. Perhaps if there were more conversation surrounding the topic of sexual health, then more occupational therapists would realize they have important knowledge to share, so that the information could reach more practitioners and clients. Or, perhaps more practitioners would realize that they are lacking some proficiency in the area, and they need to find resources to help build knowledge or skills. However, neither of the individuals thought they were doing anything special and that their colleagues were already well informed, so conversations may have failed to begin, and educational opportunities may have been missed.

Implications for Occupational Therapy

The conversations documented in this study confirm the importance of occupational therapy in enhancing the quality of life for people with physical disabilities and offer some suggestions for how to gain competence and confidence in sexual health education. The perspectives shared demonstrate the different personalities, educational backgrounds, continuing education opportunities, and communication styles possible of a therapist to enable them to consistently address sexual health concerns for clients. Continuing education routinely offered through the American Occupational Therapy Association may be a consistent way to get therapists the few hours of education necessary to feel more prepared to address sexual health regardless of work setting or geographic location.

On a smaller scale, another way to get a few hours of education to prepare practitioners to address sexual health concerns is to have a department in-service. Perhaps the therapy manager could poll the occupational therapists on the types of questions they have been receiving from clients, both questions they felt prepared to answer and ones they thought they could use a little help. This information could guide the in-service, and tailor it to the needs of the therapists and the population served.

By increasing the educational opportunities available to occupational therapists, it may cause a wider understanding of how and why practitioners can play a role in sexual health education. Once people in the profession have a solid understanding, then the conversation can expand to settings such as interdisciplinary meetings. In this venue, an occupational therapist can advocate for the needs of the client regarding sexual health, and explain how addressing these needs can have a positive impact on overall quality of life. Practitioners can educate other professionals on the skills occupational therapy can bring to sexual health education and that any conversations or requests from clients should be validated by all team members, but can be directed toward occupational therapy in particular.

Limitations

The researcher had intended to interview three participants, but due to time constraints and recruitment challenges saturation of data was not achieved and the final number of participants was two. This limitation may have been a result of a variety of factors. One possibility is that the network sampling was not an adequate means to recruit occupational therapists to participate, and the geographic region represented was relatively small. Another possibility is that the therapists who received information about

the study did not believe themselves to be qualified, since they may have known of a better candidate in the area. Third, therapists may not have volunteered if they were not actively incorporating sexual health issues into treatment. While a large sample size is not required for a qualitative study, the data may have been augmented by a more diverse sample. The inclusion of participants from a broader geographic area might have provided different perspectives, or confirmed the themes introduced by the two participants and indicating the results to be generalizable to larger population.

Future Research

There is room for improvement in the provision of sexual health education in occupational therapy. An addition to this study could be observations of the participants addressing sexual health concerns for clients with physical disabilities, specifically when treating female clients or clients in a homosexual relationship, since literature predominately addresses male and heterosexual issues.

To broaden the geographic area represented, for a more detailed picture of current practice, suggestions on ways to gain competence and confidence about sexual health education or areas for improvement could be assessed via a national survey of occupational therapy practitioners. This may update the information found by Haboubi and Lincoln (2003) and Rogers (2007). The survey could also be utilized not only to compare large geographic regions, but to compare sexual health education in urban settings versus rural settings. Another survey could be conducted to follow-up with clients who received education regarding sexual health and their experiences and views about sexuality. The information could bring the results of McAlonan (1996) and Moin et al. (2009) up to date.

To extend the findings of this study about how to become competent and confident about sexual health education and people with physical disabilities, an experiment could be conducted. The design could capture either the amount of practice required, or education hours needed, or type of mentoring program necessary, to have occupational therapists perceive themselves to be competent and confident when addressing sexual health concerns. A further extension of the current study would be to design a project to compare an occupational therapist self-report to a client report of factors following treatment addressing sexual health. The results would further indicate the components required for new or experienced practitioners to address a client in a holistic manner.

Conclusion

From the point of view of the occupational therapists in the study, sexual health concerns and sexuality issues can positively or negatively impact the quality of life for people with physical disabilities. Occupational therapists acknowledge that addressing sexual health concerns is within their scope of practice, and it is an ADL (American Occupational Therapy Association, 2008). However, in order to address these client concerns, the practitioners need to feel both competent and confident about sexual health education. The participants in the study indicated achievable ways for both new and experienced occupational therapists to increase their knowledge base, via formal and informal means, and to increase their comfort, through practice, with the topic. There are options available to practitioners to address sexual health if it is meaningful to a client. Occupational therapists have a unique skill set to focus on client factors, body functions, activity demands, environmental and psychosocial aspects of all personal goals of clients, and sexual health should be no exception.

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Appendix

Interview Format

- I. Collect demographic information
 - a. Age, sex, current/previous work settings, number of years as practicing OT
- II. Grand tour question: Would you tell me about your work experiences that addressed sexuality for people with physical disabilities?
- III. Follow-up questions:
 - a. Do you feel like a competent resource for sexual rehabilitation?
 - i. If yes, how long have you felt competent?
 - b. What steps did you take to acquire the knowledge?
 - i. School, continuing education?
 - c. Did you work with someone who helped shape your practice?
 - d. Do you feel confident in your service delivery related to sexual rehabilitation?
 - i. If yes, how long have you felt confident?
 - ii. How did you acquire this confidence?
- IV. Summary:
 - a. Do you have suggestions for therapists practicing with people with physical disabilities to incorporate sexuality concerns into practice?

Table 1

Results: Categories and Subthemes

Categories	Subthemes
1. Why Address Sexual Health?	1a. Just Part of OT's Job! 1b. Enhancing Quality of Life 1c. To Open Communication
2. How to Gain Competence in Sexual Health	2a. Formal Education 2b. Medical Knowledge 2c. Continued Learning
3. How to Gain Confidence about Sexual Health	3a. Personality 3b. Practice
4. Suggestions to New (or Nervous) Practitioners	4a. PRACTICE! 4b. Find Resources

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