Sexuality and the Initial Occupational Therapy Assessment for Adults with Physical Disabilities

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Sexuality and the Initial Occupational Therapy Assessment for Adults with Physical Disabilities

By

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A Scholarly Project
Submitted to the Occupational Therapy Department
of the
University Of North Dakota
In Partial fulfillment of the requirements

for the degree of
Master’s of Occupational Therapy

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This Scholarly Project Paper, submitted by Mandy Sherrick in partial fulfillment of the requirement for the Degree of Master's of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

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Faculty Advisor

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Title Occupational Therapy Initial Assessment for Addressing Sexuality with Adult Physical Disability Populations

Department Occupational Therapy

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CHAPTER I

INTRODUCTION

As an occupational therapy practitioner and student it is important to view and treat a client as a whole person. Historically, the profession has neglected the aspect of sexuality with the clients who have physical disabilities. In previous literature, the issue of sexuality has been presented as important to psychological well being and quality of life. This belief was generated through qualitative research accounts and clinical experience. In recent literature the focus is shifting to quantitative research supporting the idea that physical disability has an impact on a person’s entire life including their sexuality. The researchers did not stop there, they focused on the impact a lack of sexuality has on clients with a physical disability.

Throughout history sexuality has been viewed in many ways; the views have progressed throughout the generations, although it is still not a part of common conversation. To many people in current society, sexuality is no longer seen as a mere form of procreation, but is much more. Sexuality is presenting itself as a part of life, an occupation. Esmail, Esmail and Munro (2001) define sexuality as a “major component of who we are as individuals and not simply what we do sexually” (p. 268). The five components of sexuality are identified as sensuality, intimacy, sexual identity, reproduction and sexualization and that these components are all affected by one’s environment. These components are defined as follows:
"sensuality relates to our need to be aware of and acceptance of our own body through all five of our senses" (p.268),

"intimacy is described as our need and our ability to experience emotional closeness to another human being" (p.268),

"identity is another part of a sexual person and is a continual process of discovering who we are in terms of our sexuality" (p.268),

"reproductive aspects of sexuality deal with fertility and conception, and child rearing" (p.268),

sexualization is used to "describe our use of sexuality to influence, control and manipulate others" (p.268), and

when all aspects are combined, the integration is named, "sexual beingness" (p.269).

Human activities, such as sexuality, are sorted into categories defined by the American Occupational Therapy Association (AOTA) as "areas of occupation" (2002). The areas of occupation include: ADL's, Instrumental ADL's, work, play, leisure, and social participation. As history progresses, so do health care professions. Topics that were once taboos, such as sexuality, are coming to the forefront of health care practice.

According to the AOTA and their new framework for practice, domains of occupational therapy practice are described. Internally it is used to examine practice and guide interventions. Externally, it is used to begin to explain the use of occupation, function and performance factors in therapeutic services provided by occupational therapists.

The definition of ADL according to AOTA (2002) is "activities that are oriented toward taking care of one’s own body—also called basic activities of daily living (BADL)
or personal activities of daily living (PADL)” (p.620). ADL’s consist of categories represented by: bathing, dressing, grooming, eating, feeding, toileting, mobility, personal device care, bowel and bladder management, sleep/rest and sexual activity.

Sexual activity is simply defined as “engagement in activities that result in sexual satisfaction” (American Occupational Therapy Association 2002, p.620). The framework for practice states that sexuality should be included in holistic occupational therapy treatment through activity of daily living (ADL) training. Through the inclusion of sexuality as an ADL in the framework new expectations are placed on occupational therapy practitioners. According to AOTA, the framework lists a set of performance skills, performance patterns, context, activity demands, and client factors that can help in task analysis. The therapist can look at the above factors and determine the appropriate interventions to use.

Due to the fact that each area of occupation is expected to be addressed with clients, sexuality should be included in treatment. Occupational therapists and health care professionals are currently overlooking an important aspect of holistic patient care, sexuality. By ignoring this integral piece of a person’s treatment professionals are allowing clients to develop or continue low self-esteem, body esteem, sexual esteem, quality of life and poor relationships. If occupational therapy is indeed a holistic profession, it is necessary to begin addressing the issues of sexuality for persons with physical disabilities.

To explain body esteem, body image, self-esteem, sexual esteem and quality of life, the following definitions have been found in the literature.
Body image and body esteem are described by Slade (1994) and cited in Taleporos, Dip, and McCabe (2001) as “a loose mental representation of body shape, size and form which is influenced by a variety of historical, cultural and social, individual and biological factors, which operate over varying time spans” (302).

Body image is a multidimensional construct that is comprised of two dimensions, affect and cognition which, in turn, determine body esteem.

Body esteem refers to the overall positive or negative evaluation of the body (Mayer & Eisenberg, 1988).

Self-esteem is defined as confidence and self respect by Taleporos, Dip and Mc Cabe (2001).

According to Taleporos, Dip and Mc Cabe (2001) sexual esteem is the confidence in experiencing sexuality in a satisfying and enjoyable way.

Quality of life is addressed and defined by McCabe, Cummins and Deek (2000) as subjective and objective opinions across domains such as: “material well being, health, productivity, intimacy, safety, place in the community, and emotional well being” (p.117).

Now that it has been established that sexuality is within the domain of practice of an occupational therapist, it is important to look at the ways that a therapist can bring sexuality into their assessments and interventions. It is evident through research that persons with physical disabilities present with co- morbid problems with sexuality and sexual expression. In turn, their quality of life and self esteem are affected. Qualitative studies have been completed to understand sexual feelings and expression by people who
possess physical disabilities. In addition, quantitative studies have been completed in order to show the difference in outlook on sexuality between persons with and persons without disabilities and all that it implies. It is widely recommended that a P-LI-SS-IT model be implemented in order to create comfort and knowledge for both therapist and client when dealing with the topic of sexuality. In order to create a comfortable environment for clients and therapists to discuss and treat sexuality it is important to “break the ice” tactfully. One way to do so is the development of an assessment that encompasses current OT practice domains, including sexuality.

The P-LI-SS-IT model, developed by psychologist Jack Annon and cited by Friedman (1997), is designed in order to “allow people Permission to express their sexual concerns; some need Limited Information about their specific concerns, few need Specific Suggestions to solve their sexual difficulties, and very few require Intensive Therapy for sexual problems” (p. 23). It is stated that occupational therapy practitioners are qualified to provide treatment in the first three levels of the P-LI-SS-IT model by Friedman, 1997.

Permission can be offered in many ways as long as it allows clients to express sexual concerns. It is important to acknowledge that it is normal and acceptable to express apprehensions within the topics of sexuality. When a client begins to have specific questions about sexuality and requires intervention without intensive treatment, limited information is required. In order for occupational therapists to address sexuality when working with adults who have physical disabilities it is important to use a theoretical model, such as P-LI-SS-IT. In this scholarly project, the use of this model is
combined with an occupational therapy theory, Occupational Science, to create an assessment that is conducive to evaluation of sexuality with occupational therapy.

According to Willard and Spackman (1998), Occupational Science remains a theoretical basis that occupational therapy as a profession builds upon. Occupational Science consists of three major components. The components are occupational form, function and meaning. Occupation is defined as any activity that a person takes part in that has meaning or purpose to them as an individual. In this scholarly project topic, sexuality is the occupation under consideration and study. When sexuality is considered it is important to examine all three components of occupational science, specifically the form, function and meaning. Occupational form is described as a directly observable part of an occupation. In regard to sexuality, the different forms of sexuality might include holding: cuddling, intercourse, communicating, and kissing. Occupational function begins to look at ways that the occupation influences health and quality of life. Function asks the question, why and how does the person engage in the occupation? Using sexuality as an example, research shows that people with physical disabilities are less likely to have a high comfort with sexuality compared to people without disabilities; in turn, this negatively affects quality of life for them. Function also addresses the physical form of sexual expression. In this example Occupational meaning is the subjective experience of participating in an occupation and it is the personal significance that the occupation holds for that person. Sexuality is expressed for many reasons, from relationship formation, increased quality of life and expression of intimacy, among other expressions of subjective meaning.
The P-LI-SS-IT model and its relation to OT practice with the use of occupational science as a theoretical basis creates a positive context for introduction of the permission phase of the model. By introducing sexuality through *form, function and meaning* and gaining permission to talk with clients further opens a door to offering the limited information piece that may be necessary in occupational therapy treatment. The development of an assessment that does the above will be an important tool in utilizing the P-LI-SS-IT model within occupational therapy practice.

In order to substantiate the need for this scholarly project a literature review was conducted. It initially looks at the impact a physical disability has on a person and their sexuality. It further addresses the need for occupational therapists to create interventions and assessments that address sexuality. Lastly, it describes the role of health care professionals and rehabilitation teams in focusing on client centered treatment. The scholarly product is created in order to facilitate an easy and global way to introduce sexuality to clients within the rehabilitation setting. It is designed to create an environment for clients to feel comfortable in asking about their sexual issues. In addition, the scholarly project provides education and a format for occupational therapy practitioners to feel prepared and confident in providing information to address their client's sexuality concerns.
CHAPTER II
LITERATURE REVIEW

In this literature review I will present three themes regarding sexuality and occupational therapy practice. The first of which is that physical disabilities have a profound impact on sexuality. Due to this, studies address the correlation between people with physical disabilities and their self-esteem, quality of life, body esteem, sexual satisfaction and psychological well being. Secondly, it is important to recognize that occupational therapy (OT), as a profession, is well suited for communicating with clients who have physical disabilities and whose sexuality is consequently affected in negative ways. Research is present regarding domains of occupational therapy practice and supports occupational therapy’s competency to address these special needs of clients with physical disability. Thirdly, research has been completed on health care providers (including interdisciplinary teams) and their role in addressing sexuality with clients. Occupational therapy practitioners, although competent to be the lead of the team addressing sexuality, should not be solely responsible for this area of practice.

Impact of Physical Disability on Sexuality

To understand the impact of physical disabilities, it was important to examine the difference between women with disabilities and those without on their attitudes about sexuality. In a study by Vansteenhoven, Jans, and Revell (2003), 167 women were asked to complete Sexuality Experience Scales that looked at themes such as sexual acceptance,
moral attitudes, psychosexual stimulation and sexual motivation. Eighty-two women who filled out the questionnaire possessed physical disabilities. The Measure Scale for Sexual Satisfaction was also added in order to address types of sexual experiences, frequency of interactions, bodily reactions, interest, satisfaction and the availability of partners for all of the women.

Replies were analyzed using multiple statistical analyses in which the results represented the following themes: first, women with disabilities have a more negative attitude about sexual interactions than non-disabled women. One large indication in the study was that the higher the education the more the women were accepting of a variety of sexual behaviors and situations. Secondly, despite this, women with physical disabilities had less knowledge in general about sexuality, and in turn, a more rejecting and negative attitude toward sexual interactions. Beliefs about fantasizing and masturbation were about the same in women with disabilities as in non-disabled. A third theme indicated that women with disabilities were less satisfied with their sexual interactions than the non-disabled. The study indicated that all women presented with the same needs, although one-third of the women with disabilities have never experienced coitus.

Through the research process many questions were raised about the negative effect of society on women’s outlook after a disability. It was suggested that by offering education about social skills, making contact with peer groups, focusing on positive self image and increasing the feeling of self value, it may be possible to reduce the differences in satisfaction between disabled women and non-disabled women. Psychological well-being and valuing of self are important to individuals and their quality
of life (Vansteenwegen, Jans, and Revell, 2003). The quality of life for persons with a disability in relation to their sexuality needs further research.

A research article with a quantitative design by McCabe, Cummins, and Deeks (2000) took this into account. They utilized a sample of sixty people with congenital physical disability. Thirty-three females and 27 males living in the community participated in the study. The mean age of the participants was 28.64 years. The participants did not have significant intellectual or sensory disabilities. The literature review revealed that quality of life and sexuality are central to people’s lives although it does not receive attention from many health care professionals. The authors hypothesized that there was a strong association between wellness and sexuality and that despite this, people with physical disabilities do not have their sexuality affirmed. This study’s purpose was “to evaluate the association between sexuality and quality of life of people with congenital physical disability” (McCabe, Cummins, & Deeks, 2000, p. 115). It was designed to gather information and data about interrelationships of persons with physical disabilities, as well as to provide empirical data which could be used to more fully understand the role of sexual relations in people with physical disabilities quality of life. The empirical data was collected through the use of Sexuality, Knowledge and Needs Scale (SexKen) and the Comprehensive Quality of Life scale (ComQoL).

The results from the McCabe, Cummings and Deeks (2000) study found that “people with physical disability experienced low levels of sexual knowledge and experience, held negative feelings in relation to sexuality and experienced high levels of sexual needs” (McCabe, Cummins, & Deeks, 2000, p. 120). The study demonstrated that many participants have never been involved in sexual intercourse yet there was a high desire to be involved in the act.
Another strong finding was a low level of knowledge relating to sexual intimacy and interactions. The authors found a low association between quality of life and sexuality, which was not expected. It was indicated that although sexuality was important to their quality of life it was not associated with their personal satisfaction with life. The study also found that the participants were gaining their sexual education from other media rather than from friends, family and health care providers. Lastly, the authors presented a question about society’s view of sexuality of people with disabilities: do persons with disabilities have reduced expectations about sexual interactions because of their lack of confidence in sexual expression within society? This question is in common with the Vansteenwegen, Jans, and Revell (2003) study which also suggested that society plays an important role in people’s sexuality and their view of themselves. Relationships are also affected through people’s view of themselves and of their sexuality. If a partner has a decreased confidence in themselves in sexual aspect, it is expected to affect relationships. The study completed by McCabe, Cummins, and Deeks (2000) discussed persons with congenital disabilities and such things as frequency and availability of partners. Another aspect of physical disabilities that is important to address is acquired disabilities, such as spinal cord injuries and multiple sclerosis and their effect on relations due to the impact of body esteem.

Taleporos, Dip, and McCabe (2001) addressed the impact of physical disabilities as important to relationships. The study was designed to discover empirical data regarding the impact of physical disability on body image and body esteem. The research consisted of participants who reported having difficulty walking; the most common disabilities the participants reported were multiple sclerosis and spinal cord injuries.
Eighteen males and 17 females between the years of 19 and 60 (with the average age being 38 years) participated in data collection. It looked at the specific aspects of body image that were most likely to be concerning for people who possess physical disabilities. All participants were involved in a focus group discussion about how their disability affected their body esteem. They also completed the biographical information sheet (BIS) and the Body Esteem Questionnaire (PDBEQ). Information collected in a qualitative manner also included physical attractiveness, comfort with one’s body, comparison with a “normal” body, and sexual attractiveness to self and others.

The authors, Taleporos, Dip, and McCabe (2001), described body image and how it makes up body esteem through its contribution to the negative or positive outlook and evaluation of one’s own body. Body image has been indicated as a factor in body esteem, and it was noted that people who have physical disabilities are viewed negatively in society. Eventually, the negative outlook on those with disabilities affects body esteem. Women with disabilities were more likely to perceive themselves as unattractive, although they also were less likely to be concerned about changes in weight and shape.

In the study by Taleporos, Dip, and McCabe (2001), many participants spoke about their disability and how it made them feel unattractive, therefore negatively affecting their self-esteem and in turn their body esteem. The feelings of unattractiveness were influenced by the environment and by society; people who had received positive feedback were more likely to have positive body esteem. The conclusions of the article were focused on practitioners and researchers making an effort to not ignore issues that are related to body image and esteem of clients. They should assist clients in identifying
their most positive and attractive characteristics and how to draw attention to these features.

Taleporos, Dip, and McCabe (2002) continued their research with a study that “demonstrated that sexual esteem, body esteem and sexual satisfaction were strong predictors of self-esteem in people with physical disability” (p. 182). One thousand nine hundred and ninety-six people participated in the study, with ranges of no disability to spinal cord injuries, acquired brain injury and cerebral palsy. People with disabilities who were sexually satisfied and felt good about their body had a higher self-esteem; in return they felt better about their bodies and were more likely to not be depressed. In women, body esteem was related to their self-esteem. In men with disabilities, sexual esteem was related to their self-esteem. Sexual well-being and its relation to psychological well-being were presented as more important to men and women with physical disabilities than in non-disabled persons. In order to increase psychological health of persons with disabilities it was suggested that using strategies to improve body esteem and sexual well-being will be beneficial.

**Sexuality as an Area of Practice for OT**

After examining the impact that physical dysfunction has on sexuality and in turn the effect it has on the whole person, it is important to recognize that this topic is one that needs addressing. Who is responsible for helping clients with this intimate and personal part of their lives? Occupational therapists are qualified to deal with sexuality in sensitive ways.

Through a review of history, Couldrick (1998) suggested that occupational therapists play a positive role in sexual rehabilitation as well as habilitation. Couldrick
focused on the core values of occupational therapy and examined beliefs of theorists such as Maslow and Kielhofner in order to support the need for addressing sexuality issues within occupational therapy treatment. He also looked at historical issues affecting people’s attitudes toward sexuality, including personal values such as religion and culture. Couldrick’s main themes included: sexual expression and whether it is wholesome or horrid; procreation and the purpose of sex; the client as a sexual being; and occupational therapy’s values, purpose and skills.

The history presented in the literature about OT revealed the profession as having a holistic purpose and stated its strong contribution to client-centeredness. OT has a role in treatment of sexual issues secondary to disabilities, and that if sexuality is not addressed, holism can not be claimed. Couldrick (1998) stated that OT is a profession that works with intimacies such as bathing and showering but still is not clear whether sexuality is a piece of occupational therapy treatment or not. Sexuality is shown through qualitative and quantitative studies to have an effect on clients’ quality of life and self-esteem. It is stated in the article that some therapists feel that they are inadequately trained to address issues of sexuality. It also stated that some believe the OT’s role in sexual treatment is to refer to professions such as psychosocial medicine, family and martial therapy, and voluntary agencies. It also cited that currently, unofficially, OT practitioners were responsible for the majority of referrals to other professionals for intervention for sexuality issues.

According to Couldrick (1998), Kielhofner implied that although sexual activity is fundamental to persons, it was not a legitimate area of concern for OT. On the other hand, Maslow’s pyramid of motivation places sexuality at each and every level. “It
(sexuality) meets psychological needs; promotes a sense of safety and provides a source of pleasure; assists the sense of belonging and acceptance; encourages the giving and receiving of attention; and may fulfill esteem, cognitive and aesthetic needs” (p.494).

The World Health Organization (1975), as cited by Couldrick, defined sexuality as “one of the fundamental human rights of the individual” (1998, p.495). Now sexuality, including sexual function and satisfaction with sexuality, is also being considered as an important piece of the quality of life component and to the well being of individuals.

The purposes of sexual behavior according to Morris (1971), in Couldrick’s article, were formation and maintenance of relationships; satisfying a physiological need as well as to a need to explore and create; a way to fight boredom; stress reduction; and material and status gain. Through progression of history and the generations, Couldrick (1998) stated that sexual expression was becoming more outwardly accepted, although it remains a sensitive subject that is not agreed upon by everyone. This is thought to be due to the fact that it is deeply embedded in culture and religion.

According to Friedman (1997), it is important that if occupational therapists are to include sexuality and sexual expression in intervention, they should offer a beginning point and client plan in which they feel comfortable. Friedman shared the idea with Couldrick (1998) that if OT is to be considered a holistic practice it needs to include sexuality. Sexuality, according to Friedman, should be considered an activity of daily living (ADL), which is an area closely associated with occupational therapy practice. The idea behind this article was that all people are sexual and that many value their role as a sexual partner. Occupational therapy, as a profession, is true to restoring people with disabilities to role function. The author suggested that occupational therapists should ask
about ADL skills to each and every one of their clients. They should also include sexual expression as a topic of intervention. The author presented the idea that if sex is an issue that is not approached by staff at a facility, clients are less likely to feel open to asking about the topic.

Friedman (1997) suggested reasons as to why sexuality was not typically addressed in clinic situations. A major reason was that occupational therapists rely on other professions to deal with sexuality. Another reason was that occupational therapists do not personally feel adept to include sexuality into their client intervention. The article offered example situations and statements in order to make the inquiry about sexuality less uncomfortable for clients as well as therapists during the first few treatment sessions.

Therapists may not feel qualified to answer questions presented in the sexual expression area of ADL and for this reason the author suggested the use of the PLISSIT model. Permission (P), limited information (LI), specific suggestions (SS), and intensive therapy (IT) make up this model. It was recommended by Friedman (1997) that occupational therapy practitioners present the first three levels of the model to the client, minus the intensive therapy. If the therapist is unable to attain comfort in this area of ADL it was suggested that they refer to someone who can help. However, a caution was offered because the client may feel comfort in speaking with one therapist and not another. A client may feel more comfortable speaking to an occupational therapist with whom a relationship has already been established.

In order for a client to feel comfortable talking with a therapist about sexual issues, an opening must be sensitive and sincere. Kingsley and Molineux (2000) focused on the need to understand a client, and to find and use what is purposeful and meaningful
for a client and their growth. Kingsley and Molineux suggested that therapists need to
know what is important to the client because occupations are representative of people’s
“values, commitments, meanings and social context” (2000, p. 206). By understanding
who the client is and where they are coming from, it is easier to direct conversation and
intervention toward their specific needs, including sexuality.

Kingsley and Molineux (2000) conducted a qualitative research project including
six occupational therapists as participants. In this study’s results, therapists stated that
sexual orientation was not important to their clients’ treatment. The therapists who
participated stated that they were not bothered by working with people of different sexual
orientations, but on the other hand, referred to them as if they were in the same category
as a person who is an alcoholic. It was suggested that by ignoring the client’s sexuality
issues, it was indirectly not using meaningful occupations to treat the client. The study
also documented that sexuality was still taboo in society and to the interviewed
occupational therapists.

Kingsley and Molineux (2000) suggested that OTs historically have not addressed
sexuality in treatment due to the viewpoint of The Model of Human Occupation
(MOHO). Kingsley and Molineux stated that “Reilly rejected sexual and familial roles as
relevant to occupational therapy” (2000, p. 207). The study posed a concern that the
respondent occupational therapists had a limited view of occupation. This potentially
causes problems in treatment because by not considering the sexuality of the client it is
not a holistic approach involving all contexts for the client. Couldrick (1998) and
Friedman (1997) were in agreement that a disregard for sexuality could present a narrow
viewpoint when working with occupational therapy clients. Due to this concern Kingsley
and Molineux (2000) outlined recommendations for occupational therapy practitioners. The recommendations were as follows:

1. Individual therapists must increase their own knowledge of gay, lesbian and bisexual cultures.
2. Occupational therapy as a profession must increase its understanding of the relationship between sexual orientation and occupation.

The author suggested that if OT is true to its origins as a profession it will include sexuality, both heterosexual and homosexual, and then it will encompass clients' occupations.

Health Care and Team Approaches

Occupational therapists are only a piece of the puzzle when it comes to holistically treating a client. Although they play an important and leading role in creating client-centered treatment, the treatment needs to include other members on the rehabilitation team including the client and the client’s sexual partner as part of the rehabilitation team. Esmail, Esmail, and Munro (2001) completed a literature review examining the impact that disability has on a couple’s sexual and emotional relationships. Their review implied that if a health care provider wants to treat a client in a holistic manner they need to include the client’s sexual partner. The authors stated that in rehabilitation settings, client areas of sex, love, relationships, and intimacy were not addressed although they were stressful to couples’ and individuals with disabilities.

Through careful review of the literature Esmail, Esmail, and Munro (2001) found that the impact of disability on sexuality within couple’s relationships was profound and that “the disability-related physical limitations were the most frequently cited reason for
fear and feelings of discomfort in participating in sexual activities” (p. 269). Physical disabilities have been found to increase stress in relationships, decrease likelihood of marriage, and also to contribute to twice the risk of divorce.

The authors explored the changing roles and expectations that couples experience with acquisition of a physical disability. Esmail, Esmail and Munro (2001) stated that “the longer the non-disabled partner continues the caretaker role the more difficult it becomes to return to the pre-injury level of intimacy” (p. 271). The authors suggested that early intervention address independence; assistance from the partner or assistance from a professional is important to negotiate roles in order to maintain intimacy. Intimacy was recognized in the article to be as important as the physical act of sexuality. The authors stated that interpersonal intimacy should be an important aspect of treatment, rather than only the physical aspects of sexuality.

Spinal cord rehabilitation teams are an important population to reach regarding sexuality intervention. Many clients affected with a spinal cord injury are also affected within their sexual expression and participation. Booth, Kendall, Fronek, Miller, and Geraghty (2003) conducted a quantitative study that examined staff members of a spinal cord injury interdisciplinary team and their knowledge and comfort in dealing with sexuality issues. They also addressed the need for further training that the staff members wanted to see for themselves as well as for the clients.

The participants in the study by Booth et al. (2003) included staff members of Queensland Spinal Cord Injuries services (QSCIS), Australia, which incorporated the Spinal Cord Injury Unit (SIU) Spinal Outreach Team (SPOT) and the Transitional Rehabilitation Program (TRP). All disciplines employed at the facilities were invited to
participate in this study. Ninety staff participated, including nursing, medical staff, social
workers, physiotherapists, physiotherapy assistant, occupational therapists, and
occupational therapy assistants. Using the Knowledge, Comfort, Approach and Attitude
Toward Sexuality Scale (KCAASS) staff members were interviewed. The subtopics
included current staff knowledge on sexuality issues, staff comfort in addressing
sexuality, staff comfort in managing personal approaches, and staff attitudes toward
sexuality among people with spinal cord injury. In addition to the questionnaire, the top
three training needs in relation to sexual rehabilitation were elicited from the participants.

In the study by Booth, et al (2003), rehabilitation members scored lowest in
knowledge relating to assistive devices, fertility, teenage sexuality, counseling and
professional practice of providing sexuality rehabilitation. Sixty-seven percent stated that
they had limited or no knowledge about the above topics. Excellent knowledge was
reported in the areas as follows: communication, contraception, anatomy and sexual
identity. Sixty-four percent of the allied health professionals expressed that they had
limited or no knowledge relating to types of positions for intercourse. Twenty-five
percent of the professionals noted medium to high levels of discomfort when dealing with
body image, sexual preference, and pornography; although, it was comfortable to discuss
catheter placement, attitude and attractiveness. Masturbation and sexual acts made 70%
of the staff uncomfortable and they stated that they felt uniformed to deal with these.
Staff were asked to rank what they felt would be important to address within the topic of
sexuality with clients with spinal cord injury. The top three issues were: counseling,
therapies, and sexual positioning. The discussion yielded that the staff would like to be
more informed in order to increase comfort in dealing with clients’ sexuality issues. It
was noted that providing staff members with counseling and communication skills training would increase comfort in dealing with the situations. The article also suggested the use of the P-LI-SS-IT model in order to meet client and staff needs.

Summary of the Literature

When reviewing the literature it was evident that if an occupational therapist is to claim a holistic view in treating a client, sexuality needs to be included in occupational therapy intervention. It was further apparent that sexuality or the lacks thereof are important issues in people's lives. It is important to their self-esteem, body esteem, sexual esteem and relationships. In turn if sexuality becomes a topic that is readily discussed in occupational therapy sessions, it can have a positive influence on the whole person. By having this positive effect on a whole person, occupational therapists are practicing their profession and philosophy as well as practicing prevention of psychosocial dysfunction.

Through my literature review, it was evident that society and its impact on the person with a disability was a recurring theme in the research. It is important to recognize that persons who are affected with disabilities are still sexual beings and they are affected by society's views of them. Physical disabilities' impact on sexual esteem, body esteem, and sexual satisfaction is also now seen as a piece of psychological well being.

The literature consistently suggested that therapists use the P-LI-SS-IT model as a way of working with clients on sexuality issues. It encompasses many ways of creating comfortable communication between the client and therapist. If a therapist chooses to create open discussion regarding sexuality, it is important that the client and therapist feel at ease in initiating the topic. Comfort is important for both the therapist and client; if an
inviting situation is presented it becomes possible to communicate about difficult topics, such as sexuality.

One way of facilitating comfort is the development of an assessment tool designed to open a door for conversation about sexuality and any concerns the client may have, especially if they are unsure about how to approach the topic. It is the therapist’s responsibility to put the client at ease when addressing personal issues; this is the case with sexuality as well. By the use of an assessment that tactfully introduces the topic of sexuality it is likely that the client, in turn, will feel a certain level of ease in knowing that sexuality is okay to ask about and to ask for help with. Occupational therapists are trained in cultural sensitivity and multicultural issues creating a knowledge base that substantiates occupational therapists as qualified to take on this issue with clients.

Through initially broaching the subject through assessment it is likely that use of the P-LI-SS-IT model will follow nicely behind. When all work together, clients begin to get their needs met holistically. Through the meeting of needs on this level the client can also begin to develop a more positive self-esteem, body esteem and personal relationships.

The literature offers the P-LI-SS-IT model as a way to structure intervention regarding sexuality, however there remains a need for a development of an initial occupational therapy assessment to gain permission to discuss sexuality. In Chapter III, an assessment following the Model of Occupational Science will be presented to fill this void for OT practitioners and their clients.
CHAPTER III
METHODOLOGY

In the development of this scholarly project it is important to look at the process from the beginning, the idea. Through an occupational therapy course labeled Physical Aspects of OT for the Mature Adult an opportunity presented itself to do special topic reports for the classes benefit. When this student thought of special topics she thought it would be important to address sexuality with adults who have physical disabilities. The two hour presentation consisted of specific intervention ideas as well as a justification for occupational therapy clinicians to address these needs with clients. From that point forward it was a topic of interest for me.

When it came time to work on the development of the scholarly project, sexuality and its needs came to my mind. I began by reviewing the information I had discovered for the presentation and moved on to literature searches using search engines such as OT Search, Pub Med and CINAHL. Fourteen literature items spurred my interest and were about topics that dealt with sexuality and disability. Ten of the fourteen articles I read became 1-page summaries designed to begin the literature review process. The literature was compiled into categories that included Impact of Physical Disability on Sexuality, Sexuality as an Area of Practice for OT, and Health Care and Team Approaches for addressing sexuality.
The literature revealed a need for an initial occupational therapy assessment tool that would address sexuality in adults with physical disabilities. The development of an assessment required finding a strong theoretical base to execute the design. Through literature reviews and brainstorming, the P-LI-SS-IT model and Occupational Science came to mind. The assessment was broken into the three themes of occupational science and the ways they relate to sexuality. The themes were addressed by the development of questions that would gather information regarding the form, function, and meaning of sexuality for a client. In order to integrate the P-LI-SS-IT model, it was important to ask permission to assess this intimate topic, as well as to offer Permission to the client for accessible conversation about sexuality. Limited Information is offered in the assessment by asking the client if they would like further information regarding the areas or themes they may feel are affected by their disability. In order to provide Limited Information it was important to develop resources and references that would supplement the assessment.

The assessment began as a single form. It was presented in a conversation format. With further thought, it was decided that the assessment tool be offered in two formats. The two formats developed were: conversation and written. A therapist version that is used to conduct a conversational assessment and a client’s version that lacks specific occupational therapy terms and can be filled out individually by the client. References and resources were compiled for distribution to the client and for the therapist’s information. During the compilation of the references and resources, it was decided that the references should be listed according to the three occupational science themes. Clients may be offered a comprehensive list of references which addresses the three themes, or have the option of only obtaining information regarding the themes they feel
need intervention. Therapists are offered a list of references that facilitates use; it was deemed important for the therapist to offer information regarding the client’s community as well.

Once the assessment tool and references were completed, they were organized into a folder that presents the assessment in a clear format that is easy to use. The assessment was then circulated through a variety of people. The people who were asked to view the assessment and provide comments included: Jan Stube, Assistant Professor; Janet Jedlicka, Associate Professor; Kelly Loesch, Music Therapy student; Terra Nelson, MOTS; and Lynn Swanson, MOT, OTR/L, Capacity Builder for HIV prevention in North Dakota. After receiving feedback, the assessment tool and reference packet was completed with revisions deemed appropriate.
CHAPTER IV
PRODUCT DESCRIPTION

This therapist’s tool is an initial occupational therapy assessment that is designed to address the topic of sexuality. The assessment is presented in two formats, a therapist conversation format and a client’s written format. It is the therapist and client’s collective choice as to which format to complete.

The assessment is designed following two models, P-LI-SS-IT and Occupational Science. Permission questions are presented in order to obtain the right to move on with questions. Limited Information is supplied with the referenced listings. Occupational science is integrated through the use of the form, function and meaning of sexuality to the clients. Sexuality is broken into these three categories in order to differentiate problem areas within the activity of daily living, sexual activity (AOTA, 2002). After identification of barriers to sexual expression the client has the opportunity to receive references that address the topics of relevance to them which can be separate or inclusive. The therapist has an all inclusive list of references with instructions to add information from their client’s community.

The contents of this tool are listed in the appendices:

Appendix A: Therapist Conversation Guide
Appendix B: Client Written Tool
Appendix C: Therapist References
Appendix D: Client Inclusive and Separate References
CHAPTER V
SUMMARY

Addressing sexuality is an important issue for occupational therapists. By neglecting to address this issue in our clients we, as occupational therapists, are not treating the clients in holistic manner. Through review of literature, that a need presents itself to look at all aspects of our clients in order to be true to occupational therapy philosophy of practice. The literature also offers information regarding the effect that physical disabilities have on persons and their sexuality. With sexuality considered as an ADL within the OT Practice Framework (AOTA, 2002), occupational therapists should increase their participation in assessing and treating sexuality with clients.

One issue that arises is that assessments and interventions are few and far between for occupational therapists. Occupational therapy literature is sparse in identifying sexuality needs within our clients; articles and journals discovered were from professions such as nursing and psychiatry. With the core of our profession focusing on holistic treatment, working with intimate topics such as ADL’s, developing rapport building skills, it is surprising occupational therapy literature does not reflect these values with the issue of client sexuality.

Due to the lack of O.T. assessment and intervention in regards to sexuality, this scholarly project was developed to examine other profession’s findings and design an initial assessment for occupational therapy clinicians. The assessment designed was
presented in two forms: one that can be offered through conversation between occupational therapist and client, and the other as a written assessment to be completed by the client alone. The assessment was created with the use of an occupational therapy theory, Occupational Science, as well a model designed for use with sexuality called P-LI-SS-IT. The assessment follows the theoretical approach by breaking sexuality into three sub-areas that consist of occupational form, function and meaning. Permission and Limited Information are the two components of the P-LI-SS-IT model that are addressed. They are presented in the form of seeking permission to ask questions of the client, as well as offering permission to the client to ask questions of the therapist.

In order for the assessment to be completed with any relevance to the practice context it was important to develop a tool offering references to the clients regarding their issues. The client is provided with the options to receive limited information in the form of references regarding one’s specific questions throughout the assessment. The client has the option of receiving information in a full format or in separate documents so that it does not become overwhelming. The P-LI-SS-IT model was incorporated throughout the development of the assessment and reference documents. Occupational therapists are qualified, at a minimum, to address Permission and Limited Information.

Limitations are present in this project, the first of which being that the assessment was designed in a manner that may be confusing, therefore inappropriate for use with lower cognitive functioning clients. It was designed to target client with physical disabilities, but may not encompass multiple traumas that include brain injuries or other cognitive impairments. The second limitation that presents itself is that the assessment has not been through clinical trials although it has been reviewed by a variety of people,
within and outside of the OT profession. Lastly, the reference lists are only a beginning to what is available on the topic of sexuality. Each therapist will need to be confident in their abilities to link with client-appropriate resources in their community.

In the future it is recommended that this assessment be trialed within practice settings in order to facilitate standardization and data that supports its use. The trials may also reveal any need for modifications of the assessment before it is distributed. It may also be helpful to redesign the assessment in a format that could be included with patients who may present with cognitive impairments.

By using this assessment and therapist tool in clinical settings sexuality can be addressed with a feeling of ease for the therapist and the client. When a facility has this tool in place the topic of sexuality as an ADL will no longer be a taboo, and hopefully clients and therapists will feel more comfortable dealing with this important issue. Once sexuality becomes a topic within treatment occupational therapists will be closer to upholding their philosophy for practice.
Appendix A

THERAPIST CONVERSATION PROTOCOL, Page 1

Occupational Therapy Initial Sexuality Assessment for Physical Dysfunction

PERMISSION DOCUMENT

Please Read this to your client and allow them to have the opportunity to fill this out on their own, or with you through conversation. This assessment is designed to be completed in one sitting, but it can be broken into segments by function (A), meaning (B) and form (C), if desired.

Occupational therapy is a profession which is designed to address aspects of your life that are personal, such as dressing, bathing and sexual expression. This is the time to discuss and or express any concerns you may have about the impact your disability may have on your sexuality. By agreeing to continue this discussion or to fill out the information you are offering your therapist permission to ask questions regarding areas relating to your sexuality (form, function and meaning). The therapist will offer limited information to you that can facilitate healthy sexuality. This evaluation is designed to address the occupation of sexuality. This evaluation may be administered in two forms. You may be asked to complete questions through a conversation with your therapist or asked to complete it on your own by filling it out in writing. If you are uncomfortable with the format requested of you, it is appropriate to ask for an alternative. If you become uncomfortable at any point during the process please feel free to discontinue the interview or stop filling out the form.

Are you comfortable with moving on with the questioning?

If yes, please ask the following:

Would you prefer to complete the questions in a verbal format, or would you like to complete the questionnaire on your own in a written format?

Continue with questioning, or offer the written format in accordance to the client’s preference.

If no, please read this statement to your client:

Your wishes are respected. It is important to remember that if you change your mind later, your occupational therapist is (I am) willing to speak with you and offer you information regarding this personal aspect of your life.

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EVALUATION FORM A, Page 2

Occupational Function:

*Please read this question to your client.*

Permission: Are you comfortable answering questions regarding the function of sexuality. For example, the way that it will affect your life if an area of your sexuality is disrupted, or how the sexuality affected your life before disability.

*If no, move on to next set of questions on evaluation form B.*

*If yes ask for a response to each of the questions below and record their answers.*

1. Were you satisfied with your experiences of sexuality before your disability?

2. Was sexuality an important part of your life before your disability?

3. Do you feel that your quality of life will be negatively affected due to your disability?
   a. What area do you feel will be most affected?

4. Do you anticipate a change in your satisfaction of sexuality now?

5. Do you feel that any important sexual relationships will be affected by your disability?

*Please ask the following question:*

Limited Information: Would you like information regarding any of the above?

*If no, move on to next section of questions.*

*If yes, offer references regarding function. REFERENCE PAGE A*
Occupational Meaning:

*Please read this question to your client.*

Permission: are you comfortable answering questions regarding what sexuality means to you and the way it relates to your life and mental health?

*If no, move on to next set of questions on evaluation form C.*

*If yes, please ask for responses to the questions below.*

1. Do you feel like your self-esteem will be affected by your disability?

2. Do you feel that your sexuality will be affected by the way that you feel about yourself after because of this disability?

3. Do you have a partner that you feel will be affected your disability?

4. Are you confident in your role as a sexual partner?

5. What personal meaning is affected most by your disability?

6. What are you most concerned with regarding your sexuality and disability?

*Please ask the following question:*

Limited Information: Would you like any information regarding any of the above, including relationships and or a referral to a counselor?

*If no, move to next page for closing remarks.*

*If yes, offer resources or references regarding meaning. REFERENCE PAGE B*
Please read this question to your client.

Permission: Are you comfortable answering questions regarding forms of sexuality that are observable to others? Some examples of these are cuddling, and hand holding.

If no, move on to final summary on form D.

If yes, ask your client to respond to those below that they feel their physical disability may affect.

- Kissing
- Holding
- Cuddling
- Intimate Conversation
- Intercourse
- Positioning for Intercourse
- Application of “safe sex” devices, example: condom

Please ask the following question:

Limited information: Would you like information regarding ways to adapt to your situation regarding any of the above concerns?

If no, move on to final summary form, page 5.

If yes, offer references regarding form. REFERENCE PAGE C
To finalize the interview, please ask these questions and read the statements in order to conclude the session.

Do you have any questions or concerns that were not addressed through this questionnaire?

If any questions arise after I leave please remember that I will be around and you should feel free to ask questions. If it is more comfortable to communicate in a written format, you also can write down your comments/questions and I can respond.

Thank you for participating in this evaluation. Remember that your information is kept confidential in the occupational therapy office, and is for review by your occupational therapist.

The information and resources can be given to the client according to the pages they checked that they would like further information. The references are labeled with A, B, C and D to correlate with the evaluation forms. If the client wants information regarding all three use sheet D, which is inclusive.
Appendix B

WRITTEN ASSESSMENT, Page 1

Occupational Therapy Initial Sexuality Assessment for Physical Dysfunction

PERMISSION DOCUMENT

Occupational therapy is a profession which is designed to address aspects of your life that are personal, such as dressing, bathing and sexual expression. This is the time to discuss and or express any concerns you may have about the impact your disability may have on your sexuality. By agreeing to continue this discussion or to fill out the information you are offering your therapist permission to ask questions regarding areas relating to your sexuality (form, function and meaning). The therapist will offer limited information to you that can facilitate healthy sexuality. This evaluation is designed to address the occupation of sexuality. This evaluation may be administered in two forms. You may be asked to complete questions through a conversation with your therapist or asked to complete it on your own by filling it out in writing. If you are uncomfortable with the format requested of you, it is appropriate to ask for an alternative. If you become uncomfortable at any point during the process please feel free to discontinue the interview or stop filling out the form.

Are you comfortable with moving on with the questioning?

Please check one:

Yes ___
No ___

Are you comfortable with the written format? Yes___ or No____

If no, please ask your therapist for a conversation style interview.

If yes, move on to questions on page 2.

If no, your wishes are respected. It is important to remember that if you change your mind later, your occupational therapist is willing to speak with you and offer you information regarding this personal aspect of your life.
EVALUATION FORM, Page 2

Permission: Are you comfortable answering questions regarding the function of sexuality? For example, the way that it will affect your life if an area of your sexuality is disrupted, or how the sexuality affected your life before disability.

Please check one:

Yes

No

If no, move on to page 3.

If yes, please respond to the questions below; feel free to elaborate on any questions.

6. Were you satisfied with your experiences of sexuality before your disability?
   ____Yes  ____No  Comments:

7. Was sexuality an important part of your life before your disability?
   ____Yes  ____No  Comments:

8. Do you feel that your quality of life will be negatively affected due to your disability?
   ____Yes  ____No  Comments:
   a. What area do you feel will be most affected?

9. Do you anticipate a change in your satisfaction with sexuality now?
   ____Yes  ____No  Comments:

10. Do you feel that any important sexual relationships will be affected by your disability?
    ____Yes  ____No  Comments:

Would you like information regarding the above topics? Please check one:

____Yes  ____No

If no, move on to next section of questions.

If yes, your therapist will offer you information when you complete the form.
Permission: are you comfortable answering questions regarding what sexuality means to you and the way it relates to your life and mental health?

Please check one:

Yes
No

If no, move on to page 3.

If yes, please respond to the questions below.

1. Do you feel like your self-esteem will be affected by your disability?
   ___Yes ___No  Comments:

2. Do you feel that your sexuality will be affected by the way that you feel about yourself after because of this disability?
   ___Yes ___No  Comments:

3. Do you have a partner that you feel will be affected your disability?
   ___Yes ___No  Comments:

4. Are you confident in your role as a sexual partner?
   ___Yes ___No  Comments:

5. What personal meaning is affected most by your disability?
   ___Yes ___No  Comments:

6. What are you most concerned with regarding your sexuality and disability?
   ___Yes ___No  Comments:

Would you like any information regarding any of the above, including relationships and or a referral to a counselor? Please check one:

___Yes  ___No

If no, move to next page and continue with the assessment.

If yes, your therapist will offer you information/ referrals when you complete the assessment.
Permission: Are you comfortable answering questions regarding forms of sexual expression/behavior/participation? Some examples of these are cuddling, and hand holding. Please check one:

Yes____
No____

If no, move on to page 4.
If yes, please check or respond to those below that you feel your physical disability may affect.

___ Kissing
___ Holding
___ Cuddling
___ Intimate Conversation
___ Intercourse
___ Positioning for intercourse
___ Application of "safe sex" devices, example: condom

Limited information: Would you like information regarding ways to adapt to your situation regarding any of the above concerns? Please check one:

Yes____
No____

If no, move on to final comments from assessment on page 5.
If yes, your therapist will offer you information when you complete the assessment.
Do you have any questions or concerns that were not addressed through this questionnaire?

If any questions arise after I leave please remember that I will be around and you should feel free to ask questions. If it is more comfortable to communicate in a written format, you also can write down your comments/questions and I can respond.

Thank you for participating in this evaluation. Remember that your information is kept confidential in the occupational therapy office, and is for review by your occupational therapist.

Please turn in your form to your occupational therapist, and he/she will offer you the appropriate information.
These references are intended to be a starting place for therapists and clients, it is important to remember that communities differ as do needs. Please add to references and resources as needed. Remember that you are also a resource for your client and simply allowing permission for discussion about sexuality is assisting your clients in the therapeutic process.

Therapist References:


Occupational Function:


Occupational Meaning: In this section it will be necessary for therapists to insert information regarding local sex therapists and counselors.


**Occupational Form:**


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These references are offered to you in order to allow you to have access to information about your specific expressed concerns. The following are a compilation of references that may be helpful with your sexuality. Also, it is important to remember that your therapist is a good reference for you if you have specific questions.

**Occupational Function:** These references are helpful in dealing with questions regarding the function of sexuality. For example, the way that it will affect your life if an area of your sexuality is disrupted, or how the sexuality affected your life before disability.


CLIENT PRODUCT REFERENCES

Reference Form B (Meaning)

*These references are offered to you in order to allow you to have access to information that you expressed concern about. The following are a compilation of references that may be helpful with your sexuality. Also, it is important to remember that your therapist is a good reference for you if you have specific questions.*

**Occupational Meaning:** These references deal with issues regarding what sexuality means to you and the way it relates to your life and mental health


CLIENT PRODUCT REFERENCES

Reference Form C (Form)

These references are offered to you in order to allow you to have access to information that you expressed concern about. The following are a compilation of references that may be helpful with your sexuality. Also, it is important to remember that your therapist is a good reference for you if you have specific questions.

Occupational Form: These references deal with forms of sexuality that are observable to others. Some examples of these are cuddling, and hand holding.


These references are offered to you in order to provide you with access to information about your specific expressed concerns. The following are a compilation of references that may be helpful for your sexuality. Also, it is important to remember that your therapist is a good resource for you if you have specific questions.

**Occupational Function:** These references are helpful in dealing with questions regarding the function of sexuality. For example, the way that it will affect your life if an area of your sexuality is disrupted, or how the sexuality affected your life before disability.


**Occupational Meaning:** These references deal with issues regarding what sexuality means to you and the way it relates to your life and mental health


**Occupational Form:** These references deal with forms of sexuality that are observable to others. Some examples of these are cuddling, and hand holding.


REFERENCES


