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Sexuality of Older Adults With Arthritis: The Development of an Interview Schedule

Kang Dae-hyuk, M.S., O.T.R., Rowland Aurora, M.S., O.T.R.,
Miller Patricia, Ed. D., O.T.R., F.A.O.T.A.
Dept. of Occupational Therapy, College of Physicians and Surgeons
of Columbia University

국문요약

미국 노인층 관절염 환자들의 성생활: 면담을 위한 질문서 개발

강대혁, 로우랜드 오로라, 밀러 패트리시아
콜럼비아대학교 대학원 작업치료학과

일상생활동작(activities of daily living)을 주요 목적이자 치료 수단으로 사용하고 있는 작업치료사들이 그 활동 중의 하나인 성적 욕구의 표현(sexual expression)에 대해 체계적인 접근이 미진하다는 지적을 극복 하고자 본 연구가 계획되었다. 특히 만성 장애가 있는 65세 이상 연령층의 성생활에 대해 기술적으로 접근하는 방법을 고안하는 것은 상당한 임상적 의미를 부여 할 수 있다. 본 연구의 주된 목적은 관절염이 65세 이상의 미국인의 성생활에 미치는 영향과 대책에 대한 논의를 작업치료사의 입장에서 자연스럽게 유도하기 위한 질문내용을 고안하는데 있다. 본 연구자들은 광범위한 문헌연구를 바탕으로 7개항의 질문을 작성하여 10명의 노인학 전공 작업치료사들에게 비평을 의뢰하였다. 7명의 작업치료사들이 전문가로서의 세밀한 답변을 해주었고 그들은 공통적으로 일상생활 중의 하나인 성생활이 삶의 질을 향상시키는데 매우 중요한 역할을 함을 강조하였다. 이들 전문가들의 조언을 바탕으로 새로운 질문서가 완성되었다.

핵심단어: 일상생활동작; 성생활; 노년층; 관절염.

Introduction - Problem Statement

In the occupational therapy profession, sexual expression is considered an activity of daily living (Uniform Terminology Task-force, 1994), and Neistadt (1993) emphasizes that sexuality is an important aspect of self-esteem and identity. According to Conine et al. (1979), twenty-one out of twenty-six registered occupational therapists agreed that sexuality was an important dimension of activities of daily living and, therefore, evaluation and treatment for individual's sexual functioning should be included in the rehabilitation process of older adults. A number of studies found that sexual interest and the need for physical intimacy did not diminish with age or disability even though sexual activity may have declined (Levy, 1994; Neistadt, 1993; Starr and Weiner, 1981).

However, there was paucity of literature about occupational therapists' role with people who have secondary sexual problems accompanying physical or mental disability. Based on these findings, the researchers of this study believe that occupational therapists, as holistic care providers with a belief in facilitating quality of life, should be prepared to address sexuality issues with their older adult patients. One method of addressing issues of sexuality was through the development of an interview assessment, which identifies whether or not people have concerns about their sexuality and elicits the nature of those concerns. This would enable occupational therapists to intervene in secondary prevention, that is, screening for potential problems, making referrals when indicated, and beginning treatment if the occupational therapist has the knowledge and skills.

Survey research (Conine et al, 1979; Miller et al, 1993) has been conducted regarding sexual rehabilitation. However, there have not been studies to specifically identify how occupational therapists should approach this sensitive issue in assessing older adults with arthritis--which is the most prevalent disabling disease among the older population (Bush et al, 1994; Walz and Blum, 1987).

Therefore, this study addressed the following questions: 1) To what extent does arthritis restrict or alter sexual activity among older adults?; 2) What kinds of interventions can be provided by occupational therapists for older adults with arthritis to enhance their engagement in sexual activity?; and 3) What kinds of questions should occupational therapists ask older patients about their sexuality in order to develop an appropriate occupational therapy assessment of this area of function?

The main purpose of this research was to develop an interview which occupational therapists can use to assess sexuality in older adults with arthritis in order to increase the likelihood of effective intervention in this domain of functioning.

Theoretical Foundation

This study was based on the following theoretical models--the activities health model (Cynkin and Robinson, 1990), the biopsychosocial model (Engel, 1980), and the continuity model (Atchley, 1989).

The activities health model (1990) is relevant to the sexual health of older adults, since they define activities health as “a state of well-being in which the individual is able to carry out the activities of everyday living with satisfaction and comfort, in patterns and configurations that reflect sociocultural norms and idiosyncratic var- iation in number, variety, balance, and context of activities.” (Cynkin and Robinson, 1990).

Research has shown that sexuality is an important component in the quality of life of most older adults (George and Weiler, 1981; Starr and Weiner, 1981). The purpose of occupational therapy is to restore, maintain, and promote the quality of life of individuals. The activities health model supports this philosophy by encouraging the widest range of activities through which humans grow physically and emotionally, thus enhancing their quality of

life. Activities health of an individual is expressed and attained through engagement in activities. It may be said that the individual is in a state of activities health when he or she can perform socioculturally accepted activities with satisfaction and comfort (Cynkin and Robinson, 1990).

The biopsychosocial model understands the human being as one who is vulnerable to injury and illness, an emotional being with thoughts and values, and a social being who lives with others in an environment (Mosey, 1974).

The biopsychosocial model is based on a systems approach. Each system has its own level of organization which implies qualities and relationships. However, in considering this hierarchy as a continuum, each level of organization is both whole and a part of the system, meaning, each level of organization is of equal importance within the system.

The biopsychosocial model has enabled other disciplines to recognize the importance of psychosocial components in the treatment of an individual (Engel, 1980). This model provides a guide in approaching sexuality of older adults with an illness such as arthritis. The biopsychosocial model enables the clinician to extend the application of the scientific method to daily practice not deemed accessible through a scientific approach alone (Engel, 1980). This model encourages the clinician to become motivated and more skillful in psychosocial areas of patient care which supports the holistic philosophy and mission of occupational therapy.

The continuity model contributes to knowledge regarding psychosocial aging stating that, as people age, they begin to develop certain characteristics which define their personality and behavior throughout life. They tend to preserve their familiar internal and external structures in making adaptive choices. As such, if they had an interest in their sexuality in the young-adult and middle-age years, this interest is likely to continue as they age (Atchley, 1989).

Definitions

Conceptual Definitions

· Assessment - The use of skilled observation or evaluation by the administration and interpretation of standardized or nonstandardized tests and measurements to identify areas for occupational therapy services (Uniform Terminology Taskforce, 1994).

· Sensitive Questionnaire - A set of questions designed to elicit more genuine responses on a topic that may elicit deceptive responses or refusals to answer (Judd et al, 1991).

· Sexuality - The expression of sexual receptivity or interest (Webster's Ninth New Collegiate Dictionary, 1988).

· Sexual Expression - Engaging in desired sexual and intimate activities (Uniform Terminology Taskforce, 1994).

· Osteoarthritis - Noninflammatory degenerative joint disease occurring chiefly in older persons, characterized by degeneration of the articular cartilage, hypertrophy of bone at the margins, and changes in the synovial membrane. It is accompanied by pain (usually before prolonged activity) and stiffness, (particularly after prolonged activity) (Dorland's

Illustrated Medical Dictionary, 1994).

· Rheumatoid Arthritis - A chronic systemic disease primarily of the joints, usually poly articular, marked by inflammatory changes in the synovial membranes and articular structures and by atrophy and rarefaction of the bones (Dorland's Illustrated Medical Dictionary, 1994).

Operational Definitions

· Sexuality - Sexuality is defined as the conscious use of the body including caress and gesture in order to share or provide pleasure for oneself or another with or without sexual intercourse (Miller et al, 1993).

· Older Adult - Older adult is defined as any individual, male or female, over the chronological age of 65 years (Miller et al, 1993).

· Arthritis - Arthritis refers to either osteoarthritis or rheumatoid arthritis.

· Intervention - The planned therapeutic process that increases patients' knowledge regarding the effects of arthritis on sexuality and specific recommendations to enhance sexual activity of patients with arthritis.

· Interview - The process of gathering valid and desired data by engaging in conversation with an individual. For this study, the interview will elicit information regarding the older person's interest in engagement in sexual expression, any difficulty in sexual performance, the nature of difficulty, and the extent to which arthritis interferes or impedes sexuality.

Literature Review

The literature review begins with general facts about sexuality in older adults along with various factors that could influence sexual activity. Among the many variables that can affect sexuality of this population, the researchers will focus on the effects of arthritis since it is the most prevalent disabling disease among the older population. Occupational therapy interventions that can assist patients with arthritis in enhancing their sexual activity will follow. The methods and precautions for developing sensitive questions for occupational therapy assessment in the area of sexual expression will be described. In addition to discussing principles and precautions for the development of sensitive questions, examples of questions which have been used by occupational therapists will be included.

Sexuality in Older Adults

Earlier studies regarding sexuality of older adults reported that both sexual interest and the frequency of sexual activity tended to decrease with age to some degree although sexual activity persisted in later life (Freeman, 1961; Kinsey, Newman and Nicholas, 1960; Pomeroy, and Martin, 1948, 1953). Since the subjects of these studies were randomly selected, the findings may have supported a public misperception that people are less involved or less interested in sexual activity as they get older and this notion might have been perceived as a process of aging. However, this perception was challenged by survey research conducted by Starr and Weiner (1981) whose subjects consisted of 800 men and women 60 to 91 years of age. Contrary to previous

studies, more than 65 percent of the respondents reported that their interest in sex as well as their actual sex life remained stable compared to when they were younger. These findings were supported by later studies stating that the majority of physically healthy men and women remain sexually active on a regular basis into their seventies and beyond, indicating that the aging process itself was not a major factor affecting sexual activity (George and Weiler, 1981; Kaplan, 1990; Rotberg, 1987).

Some researchers suggested that a reduction of sexual activity in later life was mainly caused by other factors such as the unavailability of a partner, stereotyped psychosocial pressure, and disabilities associated with advancing age (Byers, 1983; Gupta, 1990; Levy, 1994; Weiss and Mellinger, 1990; Yeaworth and Friedeman, 1975). Traditionally, women marry men about four years older than themselves and live longer than their spouses. These facts make it almost impossible for the older woman to find another husband or a socially acceptable partner (Byers, 1983). America's youth-oriented culture also discourages older adults from being sexually active (Yeaworth and Friedeman, 1975). The advancing years may slow down older adults, however, only physical illness presents the most challenging obstacle to remaining sexually active in the later years (Walz and Blum, 1987).

Recently, researchers have begun to see sexual function as an integral part of total well being of older adults (Gupta, 1990; Neistadt, 1986a; Rotberg, 1987). “Sexuality encompasses much more than a physical act and it includes the love, care, sharing and warmth expressed between individuals” (Byers, 1983). People engage in sexual activity for many reasons, one being to help develop and maintain a relationship with another person and provide a form of communication (Sidman, 1977). It is widely believed that sexual pleasure and satisfaction in old age do not require sexual intercourse or repeated orgasms. Noncoital activity--kissing, touching, and hugging--and self stimulation may provide the much needed sexual satisfaction in later life (Gupta, 1990). Kaplan's (1991) explicit statement dispels the prevailing myths about sexuality of older adults -- “sex may become more important in a person's life with the passage of time because sexuality is among the last of the pleasure-giving biological processes to deteriorate. It is a potentially enduring source of emotional well-being at a time when more and more losses must be accepted and fewer and fewer gratifications remain available.”

The Effects of Arthritis on Sexual Activity

Several studies investigated the factors that could affect sexual activity in older adults (Byers, 1983; Gupta, 1990; Levy, 1994; Mooradian and Greiff, 1990; Weiss and Mellinger, 1990; Yeaworth and Friedeman, 1975). Even though psychological changes and social environment affected sexual activity, physical illnesses related to aging were the primary areas of concern for the researchers of the studies. Sidman (1977) and Katzin (1990) discussed some prevalent physical illnesses that

restrict or alter sexual activity among older adults. The various effects of chronic illnesses--such as arthritis, heart disease, pulmonary disease, and diabetes--on sexuality were addressed and management of the effects was suggested. Of these diseases, it has been reported that arthritis was identified as the leading cause of disability in older adults (Bush et al, 1994); and that approximately 30% of people over 65 were limited by arthritis and rheumatism (Laflin, 1990); and that arthritis comprised 48% of the specific disabilities which affected sexuality in older patients (Goldstein and Runyon, 1993).

Arthritis is characterized by inflammation of any joint of the human body. The most frequent forms of arthritis are rheumatoid arthritis and osteoarthritis. Rheumatoid arthritis is a chronic inflammatory disease of peripheral joints and cervical spine whereas osteoarthritis is a noninflammatory disease that may involve any joint but usually inflammation occurs as a secondary consequence (Melvin, 1989). In older persons, “more than one form of arthritis is often present simultaneously” (Walz and Blum, 1987), therefore, arthritis is used as an integrated term in this paper.

Most of the studies about the consequences of arthritis on sexuality agree that joint pain and stiffness are the major symptoms of arthritis which disturb sexual activity even though the degree of sexual dysfunction varies depending upon the affected sites in the individuals (Blake et al, 1987; Herstein et al, 1977; Malek and Brower, 1984). According to Goldstein and Runyon (1993), rheumatoid arthritis is a more devastating condition than osteoarthritis because it is a chronic systemic disease characterized by remissions and exacerbations. Other disorders that are included in the rheumatic diseases may severely interrupt sexual activity. Polymyalgia rheumatica causes severe pain and stiffness in shoulders and hips, especially at night (Davis, 1986). Women with either of Sjogren's syndrome or scleroderma often experience a marked vaginal dryness. Patients with Sjogren's syndrome suffer from xerostomia, dryness of the mouth due to salivary gland dysfunction, which will not result in increased salivary flow upon stimulation. This symptom with the associated rapid dental caries makes oral-genital activity painful. Similarly, atrophic proctitis, inflammation of the rectum, makes anal intercourse impossible at times (Ehrlich, 1978). Men with scleroderma may frequently experience a condition called Peyronie's disease, that causes a painful erection precluding sexual activity (Walz and Blum, 1987). According to Evans (1987), “temporomandibular joint involvement occurs in more than half of all cases of rheumatoid arthritis.” Since a deep passionate kissing is likely to cause a severe pain, a gentle closed mouth kissing without pressure on the lower lip is highly recommended in this case.

Mechanical impediments involved with hips, knees, or back may also affect sexual activity in many ways. Hip problems are considered major limitations in sexual functioning for women. On the other hand, arthritis involved with upper extremities --deformities of the fingers, poor motion of wrists, elbows, and shoulders--may also be limiting and prevent substitution of masturbation as a sexual outlet (Ehrlich, 1978). In addition, it should be noted that

medications used for the treatment of arthritis such as corticosteroid may decrease sexual desire (Ehrlich, 1978; Weiss and Mellinger, 1990).

Other factors contributing to sexual dysfunction are identified through psychosocial experience. The psychological impact of arthritis such as stress, anxiety, and depression, can affect the patient's sexuality by lowering self-esteem, which leads to a decreased interest in sexual activity. Changes in body image can lead patients to perceive themselves as unattractive. Consequently, social contact can be decreased, limiting chances to meet potential partners (Ehrlich, 1978; Malek and Brower, 1984; Sandles, 1990).

Interestingly, some positive effects of sexual activities on arthritis have been found. Patients with arthritis have reported that their sore joints were relieved as a result of sexual activities and they were helped to maintain range of motion of the limbs. It has been found that sexual activities stimulate adrenal gland production of cortisone which has been used to treat symptoms of rheumatoid arthritis (Laflin, 1990; Walz and Blum, 1987). Sorensen (1981) agrees that sex can be used as a therapeutic and preventive approach in chronic conditions such as arthritis.

Interventions for Arthritis to Enhance Sexual Functioning

Over the past 15 years, health professionals have become more aware of the role sexuality plays in the overall rehabilitation process (Dahl, 1988; Neistadt, 1986a). It has also been widely accepted that sexual adjustment was a fundamental aspect of patients' medical and psychosocial rehabilitation (Conine et al, 1979). With increasing opportunities to understand sexual dysfunction, health professionals have become actively involved in restoring or improving sexual function of older patients (Kaplan, 1991).

In practice, health professionals should respect individual differences among their older patients. Those who are sexually inactive and comfortable with that adjustment should not be made to feel inadequate, but those who are struggling with sexual problems ought to be helped to overcome them (Yeaworth and Friedeman, 1975). In the same vein, only those therapists who are comfortable discussing sexuality with their patients should intervene in this area. Otherwise, it is suggested that they refer their patients to a qualified staff member for counseling (Neistadt, 1986a).

According to Kaplan (1991), the first step is to provide older patients with accurate information about the effects of the aging process and the disease on sexuality as well as to encourage use of their remaining capacities. The second step is to try to help patients to accept biological changes in their sexuality in a constructive, positive, and realistic manner. Then, appropriate compensatory and therapeutic techniques and positive constructive attitudes are recommended as two keys to successful restoration of sexual functioning in older patients. In order to achieve a maximum treatment outcome, a valid evaluation which includes an assessment of both organic and psychological parameters of the individual's problem should be administered (Kaplan, 1990).

There are several models which can be applied by therapists to determine the method of counseling. One model devised by Annon (1974) (cited in Goldstein and Runyon, 1993; Neistadt, 1986a) is the "PLISSIT" model which consists of four levels, and the first three levels are appropriate for occupational therapy intervention. The first level is the "permission level." In this level, the therapist listens to a patient in a "nonjudgmenal, knowledgeable, and relaxed manner." The patients need the assurance that they are not alone and their concerns are "normal." The second level, "limited information," is concerned with providing information to the patient regarding specific sexual concerns and offering suggestions which could minimize these concerns. The third level, "specific suggestions," allows the therapist to develop specific interventions based on the individual's sexual history. The patient must provide the therapist with his or her brief sexual history in order for the therapist to develop a treatment plan which is most effective for the person. This level, in particular, can be used by occupational therapists to determine the types of interventions for specific disabilities, such as arthritis (Neistadt, 1986a). The fourth level, "intensive therapy," involves the application of the long-term therapy to the patient. This level of treatment should be performed by a certified sex therapist or psychologists and psychiatrists with expertise in this area.

In the case of arthritis, patient education is critical. Knowledge of the physiologic changes associated with aging process and arthritis can greatly enhance adjustment and enjoyment of sexual expression (Laflin, 1990). The education includes educating about timing and positioning. An example of a metaphor regarding sexual expression is that a matinee may be preferred over early morning, night, or evening hours since severe pain usually attacks the victim around bed time, during the night, and upon awakening in the morning (Ehrlich, 1978). Laflin (1990) provides an extensive set of pain reducing positions that can be introduced during the counseling sessions. It is essential that sexual partners communicate openly about which sexual activities are pleasurable and which may cause pain (Arthritis Foundation, 1990; Walz and Blum, 1987). The following interventions can be introduced by occupational therapists in addition to counseling.

· Home exercise program (Stenstrom, 1994) for joint mobility and joint protection techniques. The individual who is in good physical condition and engages in regular exercise will be able to engage in sexual activity sooner than the sedentary individual (Sorensen, 1981).

· Application of thermal modalities--ice or heat (Laflin, 1990).

· Use of a waterbed (Walz and Blum, 1987).

· Placing pillows under painful limbs (Walz and Blum, 1987).

· Various pain reducing positions available

· Emptying the bladder before sex can facilitate more comfortable love play and sexual exchange (Laflin, 1990).

· Providing emotional support (Melvin, 1989).

· Taking analgesic or anti-inflammatory

medications thirty minutes to one hour prior to engaging in sexual activity (Enrlich, 1978).

Occupational therapists are in an excellent position to provide information on sexual functioning (Neistadt, 1993) and if occupational therapists become familiar with sexual components in different realms of society, they can be better prepared to assist the patient in this activity of daily living (Dahl, 1978).

The Development of Questions Regarding Sexuality

In developing an assessment tool, one must clearly construct questions which can be understood by the respondents. The goal in developing questions is to learn what the respondents know, feel, expect, prefer, or have done concerning their sexuality (Judd et al, 1991). The response process of the patient is the basis for the development of the questions. The development of these questions should consider what might be sensitive for the patient. The terminology in the questions should be exact, reflecting what the question content means. However, at the same time, terms must be simple. “Ambiguous words and biased words should be avoided” (Judd et al, 1991) since they have the potential of causing confusion and difficulty in answering the question.

In the development of questions one must consider many factors. The level of specificity is an important factor in dealing with attitudes and beliefs (Judd et al, 1991). The length of time is also important in asking questions; the shorter the interval, the better. The number of questions can also affect the respondent's behavior. Starting the question is an important part of the development of questions. This can reduce bias in the responses given by the respondents. Some respondents may respond to the structure of the questions rather than the question itself. In developing the structure of a question, qualifications and conditional clauses should come first. It is also important to simplify the respondent's task when developing the structure of the question. For example, instead of asking the percentage of sexual experiences an individual has, it is preferable to ask for monthly sexual experiences which allows the individual to respond without difficulty (Judd et al, 1991).

In developing questions, one must determine if the questions will be open-ended questions, closed-ended questions or a combination of both. Although open-ended questions are more time-consuming and are less cost efficient than closed-ended questions, the benefit of choosing open-ended questions is in giving the respondent an opportunity to relate his or her feelings more completely within a relevant context and culture. To extract the information of personal interest from the older person, use of closed-ended questions may not be feasible. Unlike open-ended questions, closed-ended questions give the individual either the forced choice of “yes” or “no” or more than two options and the respondent must choose the option closest to the respondent's agreement. Open-ended questions do not limit the individual's response and they are often more motivating to respondents (Judd et al, 1991)

which is an important factor in this research. In developing questions, general questions should come first before specific questions. This will reduce the respondent's anxiety in trying to decipher what the interviewer is asking. The sequencing of questions also plays an important part in the respondent's feedback. If the respondent finds the questions difficult to follow, this discourages the respondent from completing the interview (Judd et al, 1991).

In developing questions, a cognitive approach, which includes four stages--comprehension, retrieval, estimation and judgement, and response, has been proven effective in increasing response rate (Jobe and Mingay, 1989). The technique used to understand this cognitive approach is based on a procedure called the verbal report. This involves thinking aloud, which encourages the subjects to verbalize their thoughts as they answer the questions posed to them. The patient must have the ability to interpret the question in order to recall relevant information and judge the question posed, thereby giving a response. The interview is a means of identifying the stages that pose problems for the individual's response (Bercini, 1992). The verbal report technique represents the clinical or evaluative approach of cognition. In applying the cognitive approach it has been shown to reduce the respondent's error in health surveys (Jobe and Mingay, 1989; Willis et al, 1991).

The ability of the interviewer to have a successful interview is dependent on the construction of well-developed questions. This leads the topic into the development of interview skills which facilitate the interview process and results in a successful interview response. The other important aspect in the process of interviewing is creating a friendly atmosphere. The introduction should be brief in the explanation of the purpose of the study, the agency sponsoring the research, and the introduction of the researchers (Judd et al, 1991). An important factor in asking questions to the respondent is the tone used in asking the questions. The interviewer has to be prepared to ask questions conversationally rather than asking them stiffly. The interviewer should be cautious in the approach of recording the responses in order to minimize bias. Paraphrasing the response distorts the meaning of the respondent's answers to the questions.

In developing questions, one must have a clear conceptual idea of the validity of the assessment. This supports the importance of pretesting in the development of questions (Bercini, 1992). An important method of avoiding unwarranted assumptions when devising questions is to ask a preliminary question pertaining to the respondent, and follow with the question of interest if the respondent falls into this category. Direct questioning on sensitive topics, such as sexuality, may elicit a deceptive response (Bercini, 1992). One of the most important aspects when interviewing people regarding their sexuality is developing a good rapport with the respondent. Jobe and Mingay (1989) suggested that, in asking questions based on private or sensitive issues, the best results come from long questions rather than short questions, and open-ended questions rather than closed-ended ques-

tions. These questions should also be posed in third person rather than first or second person. An example would be "some people have difficulty with their sexual activity in the evening. Do you share this problem also?"

Literature revealed several inventories that attempted to measure some aspect of sexual behavior. These included Sexual Interaction Inventory (LoPiccolo and Steger, 1974), Index of Sexual Satisfaction (Hudson, Harrison, and Crosscup, 1981) and Sexual Adjustment Questionnaire (Waterhouse and Metcalfe, 1986) all of which used scales or "true or false" methods. These inventories may be efficient in collecting quantitative data of sexual behavior for purposes of research. However, these self-report, closed-ended questions may limit the individual's response and motivation in a clinical setting (Judd et al, 1991).

Several attempts have been made to assess sexual functioning in the occupational therapy profession. The widely used method is the use of a self-report problem checklist (Andamo, 1980). Andamo's checklist included concerns about all areas of occupational performance such as housekeeping, fear of unemployment, reduced social life and worries about sexual activity due to arthritis. If the patient shows concern about his or her sexuality, occupational therapy intervention should be addressed. However, it can be argued that the checklist approach does not lend itself to the patients expressing their concerns about sexuality. Andamo (1980) recommended a natural way of initiating discussion about the patient's sexuality -- "Today, we begin with an evaluation to identify the abilities and limitations you may have in certain activities that are necessary in your re-entry to the community and the performance of your various roles, as a homemaker, a sexual partner and other roles." Neistadt (1993) shared the similar perspective with Andamo in approaching sexuality issues. They suggested a concrete introduction statement as an opening between the patient and the therapist. "People who have been in the hospital for a while or who are experiencing difficulties like yours often have questions about sexuality. I have some information about sexuality and disability, so I could try to answer your questions. If I do not have the answers to your questions, I will try to find the answers for you or refer you to someone on staff who knows more about this area than I do" (Neistadt, 1993). However, she pointed out that a simple closed-ended question, such as "Do you have any concerns about sex?" would be more appropriate for older adults with limited cognitive abilities. Kligman (1991) also recommended that clinicians use non-judgmental, open-ended questions in order to elicit sexual concerns.

The Canadian Occupational Performance Measure evaluation tool (Law et al, 1991) assesses sexual functioning through the use of closed-ended questions such as "Can you engage in sexual activity?" and "Are you satisfied with the way you engage in sexual activity?" However, closed-ended questions have been criticized for their inappropriateness in approaching private or sensitive issues (Jobe and Mingay, 1989).

Occupational therapists can initiate a

question about sexuality by asking “Many people with arthritis often have concerns about their sexual function. Please tell me about any concerns you have at this time” (Goldstein and Runyon, 1993). If the patient reveals his or her concerns, the therapist can ask additional questions, but if the answer is “No”, the occupational therapist should let the patient know that they are always available sources for assistance in this area and the therapist would be happy to discuss any sexuality issues further or make a recommendation to an expert in sexual dysfunction, eg. a urologist (Walz and Blum, 1987).

Methodology

Study Design

This study was an exploratory, descriptive study. Some literature has been published on the topic of sexuality and older adults. However, scant research has been conducted in the domain of sexuality regarding people over 65 years of age who have arthritis. The purpose of this study was to develop sensitive questions for older adults with arthritis regarding their sexuality. The questions are to be used as an occupational therapy evaluation tool which may be incorporated into an activities of daily living (ADL) assessment for older adults with arthritis. This research described the process of developing sensitive questions regarding sexuality of older patients with arthritis. This process was based on an investigation of the literature, and information from sexuality questionnaires used by health care professionals who focus on geriatric issues and older adults with arthritis, and personal communication with occupational therapists who are specialists in gerontology/geriatrics or who incorporate sexuality issues into their ADL evaluation.

This was also a methodological study because the interview schedule developed by these researchers through this study is expected to be used in evaluating the area of sexual expression in ADL assessment for patients with arthritis who are over 65 years of age.

Subjects

The subjects in this study included ten occupational therapists; some of whom have specialized in work with the older population, and others who have expressed interest in sexuality of older adults. They were asked to make recommendations as to what questions they deemed appropriate and to provide feedback on the first draft of the interview schedule developed by these researchers.

Procedure

The method of developing an interview schedule for patients with arthritis regarding sexuality included seven steps. The first step included a thorough literature review regarding sexuality of older adults. The second step involved gathering and analyzing sexuality questionnaires currently used by health care professionals. The third step involved studying how to develop a sensitive interview schedule. The fourth step required asking occupational therapy experts what questions they would recommend in assessing sexuality issues. The fifth step entailed the development of

an interview schedule based on the literature review, and telephone conversations with two occupational therapy experts, and the judgement of these researchers. The sixth step consisted of sending a package which included a cover letter, a demographic questionnaire, the first draft of the interview schedule, and a commentary form to ten occupational therapists who have either had an interest in sexuality of older adults or have specialized in care of older adults. The occupational therapists were asked to critique the interview schedule and offer their suggestions for modification of the interview schedule. The seventh and final step involved the revision of the interview schedule based on recommendations from the occupational therapists, the research advisor of this study, and from these researchers' viewpoints.

Results

Preliminary Interview Schedule Reviewed by Occupational Therapy Experts in Geriatrics-Gerontology

We would greatly appreciate your comments and recommendations regarding the interview questions attached. A form for your comments follows the interview questions. The purpose of this assessment is to identify problem areas (physical, psychological, or social) that limit sexual activity of older adults with arthritis. After administering the following interview schedule, the occupational therapist should be able to determine whether further occupational therapy treatment is indicated (eg. suggestions for positioning) or a referral is necessary based on the findings.

Interview

① Occupational therapists are interested in helping people accomplish all their daily activities to the greatest extent possible. Many people with arthritis often have concerns about their sexual functioning. Could you tell me about any concerns about performing sexual or intimate activities you may have at this time or concerns you have had in the past year?

Probe questions may follow regarding arthritis, eg. A) How does pain limit you sexually?; B) How does movement limit you sexually?

② To what extent is sexual activity meaningful or important to you now?

③ In the past, how important has sexual activity been to you?

④ How do you feel about your current sexual activity in terms of frequency? Is it as often as you would wish?

⑤ How do you feel about your current sexual activity in terms of satisfaction? Could you tell me more about why you feel this way?

⑥ Some people, as they get older, complain of a variety of things which limit intimacy or sexual engagement, not just about arthritis. For example, not having a partner or fear of not being an adequate sexual partner. Do any of these limitations in participating in sexual activity apply to you? Does anything else come to mind?

Demographic Results

Ten occupational therapists received the interview schedule and feedback form. There were eight returns, however, one respondent did not feel experienced in this

domain, leaving seven responses. Two respondents have specialized in gerontology/geriatrics for more than twenty-five years. One respondent has specialized in perceptual/cognitive dysfunctions in the adult population for twenty years. Four other respondents specialized in adult rehabilitation settings with experiences ranging from one and a half to eight years. Five out of seven therapists responded that they often addressed issues of sexuality in the clinical setting, while they always addressed these issues in an academic setting.

Table 1. Demographics of occupational therapy experts

(Respondents)	Title	Specialty Area as Reported by Respondents	Years in Practice
1.	Director, Community Health Educator	Education, Gerontology	25
2.	Per diem Therapist; Adjunct Faculty, O.T. Program	Subacute Care; Teaching	4
3.	Assistant Professor and Director, O.T. Program	Aging	27
4.	Professor, O.T. Program	Neurorehab; Mental Health	5
5.	Supervising Therapist	Long-term Rehab	1.5
6.	Assistant Director	Adult Physical Disabilities	8
7.	Assistant Professor, O.T. Program	Perceptual-cognitive Dysfunction in Adults	20

Table 2. Therapists' use of sexuality in clinical practice and/or teaching

(Respondents)	Q# 6. How often do you personally address issues of sexuality with your clients?	Q# 7. How often do you teach about assessment of sexuality to students?	Q# 8. How often do you teach about intervention in sexuality to students?
1.	rarely	N/A*	N/A*
2.	often/sometimes	often	often
3.	often	often	often
4.	N/A*	always	always?/often?
5.	often	always	always?/often?
6.	often	always	always
7.	often	always	always

* Not applicable

Respondents' Comments on the Interview Schedule

Q# 1. What do you like about the interview schedule?

* It taps crucial questions and uses a limited number of questions.

* Open-ended questions. Assume the client does have a sexual history and a current involvement in sexuality.

* That you're doing it.

* It is generally open-ended and sensitively worded.

* The interview includes a history, present status and future hopes in sexuality. I also like the open-ended questions which can lead into a more detailed discussion.

* I like it's ability to be used for any person in the geriatric population. People who have a variety of different interpretations of sexual behavior and/or lifestyles would not be excluded from this interview. This way the questions and introduction to the interview are phrased is very sensitively stated.

* Holistic look at sexuality; sexual activity viewed in terms of it's meaning to the individual.

Q# 2. What do you dislike about the interview schedule?

* Isolates sexuality as a separate issue. Doesn't acknowledge that this is a difficult subject to speak about; doesn't provide an "easy out" for those who do not wish to discuss this subject.

* Doesn't put sexuality in a modest context needs more emphasis on social.

* Some of the wording is a bit clumsy. I've made some changes.

* Sexual functioning is just one aspect of sexuality, and so when you say/ask "How does pain limit you sexually?" you are limiting the interview to be just about sex and not about other expressions of one's sexuality. For instance, if the question read, "How does pain limit expression of your sexuality?" -(of which sexual functioning could be listed as a part). This could take into account a lot of other aspects of this domain of functioning eg. putting on make up, dressing up, going out and socializing with potential partners, etc.

Q# 3. What would you delete in the interview schedule?

* Nothing-change wording in question number one.

* Question number three seems irrelevant to client's current needs, and may be considered prying. Vague about "sexual activity"-what does this include?

* Re-order

* Question number four-emphasis in sexuality counseling should be on quality of intimacy, not quantity.

Q# 4. What would you add to the interview schedule?

* Consider a scale for number two and number three. Many people have problems because of medication side effects, especially men. Sometimes they aren't aware the medication is responsible.

* Could be clearer as to what assistance will be made available to clients who do have sexual concerns. What do you have to offer them? If this isn't clear, they may be reluctant to share concerns. Eg. after asking person to "tell me about any

concerns," you could ask if they'd be interested in written information, group education. You could ask if they might want this at some other time too.

* Something that gets the respondent thinking about the vast variety of sexual activities, all the ways of expressing love and affection. For eg. if patient's main concern is kissing, caressing or hugging, your questions may not elicit this information.

* I would mention before the interview that sexuality issues are common and how an occupational therapy could be helpful (eg. what areas of sexual functioning and/or sexuality), so that the client is "prepared" for the interview.

* You might want to further define intimate activities because you separate it out from sexual activities. How do they differ? I would add some questions which would address other aspects of sexuality.

* Question one-as edited. This question should be an open invitation to either discuss sexuality or close the topic of discussion.

Q# 5. Overall, do you consider this an effective way to elicit information re- garding sexuality? Explain.

* Yes-I like the open-endedness of questions.

* Yes-It'll "open the door" to sexual concerns. However, one format doesn't fit all. It may be too personal for some people and not supportive enough for others.

* I need to know more-are you doing a focus group format? With content analysis?

* Generally-yes.

* Overall, yes. I would, however, provide the client with the option of a person-to-person interview or to fill it out I (this may have been considered already).

* No, not to elicit information regarding sexuality but yes for eliciting information about sexual functioning.

* Yes.

Q# 6. Comments.

* Not clear at what point you will terminate the questions. What happens if they say "no" to question one? Do you continue the interview? I'm not clear what the purpose of this interview is-to gather information or to identify client need for clinical intervention on sexual function. Who will be doing the interview (eg. regular therapist, student?) What is the context? How will it be introduced? This affects it's effectiveness.

Revised Interview Schedule

The revised interview schedule was developed based on the researchers' careful study of the occupational therapy experts' responses.

Guidelines for Occupational Therapist

· A positive rapport between the therapist and the patient can be built while explaining the purpose of the interview.

· The interview schedule can be administered with other areas of ADL assessment.

· It is important that the occupational therapist inform the patient of possible assistance which he or she can provide (eg. brochure, group education, and referrals).

· A period of silence should be permitted for any question which has two parts.

· If the patient should answer "no" to questions 1, 2, and 3, the interview should be terminated.

*** Introduction to purpose of the interview schedule**

(Wording should be adapted for the comfort level of both the therapist and client and for the understanding of the client).

The purpose of this interview schedule is to identify problem areas (physical, psychological, or social) that limit sexual expression of older adults with arthritis. Sexual expression is defined as engaging in desired sexual and intimate activities which include hugging, kissing, caressing, masturbation, and intercourse. Occupational therapists are interested in helping people accomplish all their daily activities to the greatest extent possible. People with musculoskeletal problems often have concerns about how their bodies perform while expressing their sexuality. For example, we can help you with moving about more comfortably, and we have some written materials we can give you. I am going to ask you some questions so I can understand your concerns. If you feel uncomfortable at any time during the interview, you are welcome to terminate this interview.

1) How important is sexual expression to you now?

2) In the past five years, how important has sexual expression been to you?

3) Are factors such as difficulty moving or pain limiting your sexual expression? Is there anything else limiting your sexual expression that you would like to tell me about?

(If all the above responses have been answered "no" terminate the interview, otherwise proceed with the questions)

4) How do you feel about your current sexual expression in terms of frequency? Is it as often as you would wish?

5) How do you feel about your current sexual expression in terms of satisfaction? Could you tell me more about why you feel this way?

6) Sometimes medications can have an affect on your desire for sexual expression. What medications are you taking? Do you feel your medications may affect your interest in expressing yourself sexually?

7) Some people, as they get older, express a variety of ways in which they are limited in their ability to engage in sexual expression, for example, not having a partner or fear of not being an adequate sexual partner. Does this apply to you? Does anything else come to mind?

An ending statement is recommended in the closure of the interview schedule. The following statement can be used as an example, "I know this is the first time we have talked about sexuality. If something should come to your mind later, please discuss this with me anytime in the future."

Discussion

The comments from the occupational therapy experts in geriatrics/gerontology were considered in the revision of the

interview schedule. However, some comments were rejected based on the literature review and the study purpose. Two respondents indicated the term, sexual activity, can be perceived in various ways. The definition of sexual expression was clearly re-stated in the revised interview schedule to minimize any confusion. The respondents appreciated the structure of the questions being open-ended which can be individualized in eliciting sensitive issues.

One concern was the isolation of sexuality issues. In response to this concern, it was encouraged that the revised interview schedule be administered with other areas of ADL assessment. One concern for the patient was the limitation of opportunity to terminate the interview process. The researchers acknowledged this concern by addressing this issue in the introduction section of the revised interview schedule.

Although one respondent argued sexuality issues should focus on quality rather than quantity, the researchers felt frequency of sexual expression may be an important factor for some individuals. A respondent implied that past sexual expression was irrelevant to current needs. However, based on the Continuity model (Atchley, 1989), the researchers decided to include the questions regarding sexual expression in the past. A respondent recommended the use of a scale as part of the interview schedule. This idea was rejected because the use of a scale would limit the questions to a closed-ended format which the researchers intentionally avoided.

One respondent suggested the inclusion of a question regarding the effect of medication. This idea was well taken by the researchers and included as part of the interview schedule. One concern raised by respondents was the clarity of assistance which would be offered by the occupational therapist such as written information and group education. In the revised interview schedule, this concern has been incorporated into the guidelines and introductory statement which the occupational therapist is to follow. Most respondents agreed that the interview schedule would elicit information regarding sexuality. One respondent questioned who would administer the interview schedule. Ultimately, this interview schedule will be administered by the occupational therapist. However, the revised interview schedule will be piloted by students continuing this project to ascertain validity of this interview schedule.

Limitations

Although the size of the sample was small (n=7), the quality of the responses were thoughtful and comprehensive, yielding a valuable outcome. The commentary section was limited to general responses on the interview schedule. To encourage more efficient responses, the researchers could have had commentary questions related to each question of the interview schedule. However, many respondents chose to comment on each question despite the lack of request for such.

In analyzing the responses, the researchers provided justification for rejecting and/or accepting comments. However, the researchers recognize that their judgement may have been biased. In the demographic

questionnaire, the scale could have included the option of "sometimes" between "often" and "rare," leaving the respondents with more choices.

Older adults were not included as "experts" in developing the interview schedule. The researchers have not yet provided a method of assessing the validity and reliability of the interview schedule. Further research is indicated to obtain validity and reliability of the interview schedule.

In distributing information packets to the respondents, the researchers may not have clarified sufficiently the purpose of the study, the context in which the interview schedule would be administered, and the possible role of occupational therapists after administering the interview schedule. The researchers developed the interview schedule with the assumption that it would be applicable for older adults in a variety of settings.

Implications for the Occupational Therapy Profession

The most salient implication from the discussion of this research was the need for an assessment tool which would adequately evaluate the sexuality of older adults. As a response to this need, the advisor and the researchers have developed the revised version of the interview schedule based on the comments from occupational therapy experts in gerontology /geriatrics.

The interview schedule would provide information that could be used in the first three levels of the PLISSIT model approach: the first level, "permission," the second level, "limited information," and the third level, "specific suggestions." The researchers believe if occupational therapists were knowledgeable about the PLISSIT model approach, they would be better prepared to administer the interview schedule in gathering relevant information about sexuality of older adults.

The three theories--the activities health model, the biopsychosocial model, and the continuity model-employed in this research gave the researchers guidelines in addressing sexuality issues with older adults. It was anticipated that the implications for occupational therapy would be far reaching as integration of the knowledge base of sexuality into practice becomes a reality. This would fulfill the biopsychosocial philosophy of occupational therapy and the promotion of activities health, while enhancing the continuation of quality of life for many older people.

This interview schedule is expected to be utilized in future studies as well as in assessing activities of daily living for occupational therapy intervention. This study will be continued and the interview schedule will be piloted in the next academic year at Columbia University.

Conclusion

In the occupational therapy profession, sexual expression has been defined (Uniform Terminology Taskforce, 1994) as an important function of activities of daily living. The high response rate of respondents to this study reflected this belief. The lack of an assessment tool of sexual functioning led the researchers to develop

an interview schedule which could be incorporated into an activities of daily living assessment.

The main purpose of this study was to develop an interview schedule for older adults with arthritis regarding their sexuality. Occupational therapists are in a position to act as liaisons between patients and other medical experts since occupational therapists usually spend more time with patients per session than physicians. Occupational therapists tend to develop close relationships with their patients, therefore, allowing the patient to feel comfortable discussing sensitive issues such as sexuality. The interview schedule will allow occupational therapists to determine if the patient is having problems socially, psychologically, biologically or a combination of these domains of function. This interview schedule will enable occupational therapists to appropriately refer patients to other medical experts when necessary and to intervene appropriately. These researchers believe that it is helpful to include questions regarding sexual functioning as part of an overall assessment of activities of daily living.

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