Sexuality and Serious Mental Illness

Edited by

Peter F. Buckley, MD

HARWOOD ACADEMIC PUBLISHERS

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Chronic Mental Illness

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Peter F. Buckley, MD
Case Western Reserve University
Cleveland, Ohio, USA

harwood academic publishers

Australia Canada China France Germany India
Japan Luxembourg Malaysia The Netherlands
Russia Singapore Switzerland

Amsteldijk 166
1st Floor
1079 LH Amsterdam
The Netherlands

British Library Cataloguing in Publication Data

Sexuality and serious mental illness. - (Chronic mental illness ; v. 7 - ISSN 1066-7407)
1. Mentally ill - Sexual behavior
I. Buckley, Peter F.
362.2

ISBN 90-5702-598-1

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INTRODUCTION TO THE SERIES

This series on chronic mental illness is a result of both the success and failure of our efforts over the past thirty years to provide better treatment, rehabilitation and care for persons suffering from severe and persistent mental illnesses. The failure is obvious to all who walk our cities' streets, use our libraries or pass through our transportation terminals. The success is found in the enormous boost of interest in service to, research on and teaching about treatment, rehabilitation and care of those persons who, in Leona Bachrach's definition, "are, have been, or might have been, but for the deinstitutionalization movement, on the rolls of long-term mental institutions, especially state hospitals."

The first book in our modern era devoted to the subject was that by Richard Lamb in 1976, *Community Survival for Long-Term Patients.* Shortly thereafter, Leona Bachrach's unique study "Deinstitutionalization: An Analytical Review and Sociological Perspective" was published. In 1978, the American Psychiatric Association hosted a meeting on the problem that resulted in the publication *The Chronic Mental Patient.* This effort in turn spawned several texts dealing with increasingly specialized areas: *The Chronic Mentally Ill: Treatment, Programs, Systems* and *Chronic Mental Illness in Children and Adolescents,* both by John Looney; and *The Chronic Mental Patient/II* by Walter Menninger and Gerald Hannah.

Now, however, there are a host of publications devoted to various portions of the problem, e.g., the homeless mentally ill, rehabilitation of the mentally ill, families of the mentally ill and so on. The amount of research and experience now that can be conveyed to a wide population of caregivers is exponentially greater than it was in 1955, the year that deinstitutionalization began.

This series will cover:

- types of intervention, e.g., psychopharmacology, psychotherapy, case management, social and vocational rehabilitation and mobile and home treatment;
- settings, e.g., hospitals, ambulatory settings, nursing homes, correctional facilities and shelters;
- specific populations, e.g., alcohol and drug abusers, the homeless and those dually diagnosed;

– special issues, e.g., family intervention, psychoeducation, policy/financing, non-compliance, forensic, cross-cultural and systems issues.

I am indebted to our hard-working editorial board as well as to our editors and authors, many of whom are involved in both activities.

This latest volume deals with a subject that no one has tackled to date and that provokes much concern: sexuality in the seriously mentally ill. It is comprehensive and practical, helpful yet academically rigorous, and useful to so many of us in the field who have struggled with these issues. Its editor and authors are able to communicate the many complex facets of this problem engagingly.

Future books in the series will deal with legal issues, housing and residential care, the chronicity of substance abuse, inpatient care, ethics and psychopharmacology – all as related to the treatment, care and rehabilitation of the chronic mentally ill. I hope you'll look forward to them as much as I do.

John A. Talbott, MD

PREFACE

Sexual activity among persons with serious mental illness is an issue of clinical, social and legal concern. Accurate delineation of the prevalence of sexual activity in this population is obfuscated by misconceptions and by the intensely personal nature of this behavior. Moreover, sexuality in persons with serious mental illness has traditionally been considered an uncommon occurrence because of anhedonia, psychosocial impairment and medication-induced sexual dysfunction. Recent research challenges these assumptions and suggests that as many as 50% of those with serious mental illness will engage in sexual activity. Individuals may become sexually active as an expression of normal sexuality, or as a consequence of psychotic symptoms. Additionally, the institutional subculture may foster such behavior. This volume provides a timely and authoritative overview of critical aspects of this important topic.

The book is timely because of several developments in mental health. First, the current culture of psychiatric consumerism promotes personal autonomy and the expression of fundamental human rights, including individual choice among persons with mental illness. Second, the allied movement of advocacy places emphasis on patient involvement in their care and on the importance of respect and human dignity. Third, the recovery model stresses the personal experiences of patients with mental illness, including the capacity for personal fulfillment and sexuality. This model holds primacy in current perspectives on rehabilitation for persons with mental illness. Fundamentally, the recovery model views normalization as the key approach for success. Fourth, the array of new and more efficacious treatments are resulting in improved outcomes and a greater likelihood that patients will achieve satisfying life experiences, one of which is intimacy. At the same time, we have become increasingly preoccupied with the issues of competency, informed consent and the legal obligations of the mental health system to protect vulnerable individuals and the community at large.

In the opening chapter, Dr. Buckley and colleagues review the epidemiology, patterns and clinical characteristics of sexual activity among persons with severe mental illness, with respect to both hospital and community settings. In the second chapter, Dr. Deegan, a psychiatric consumer and nationally known advocate, discusses these

complex issues from the patient's perspective. She describes human sexuality as a component of the recovery process for persons with mental illness. In considering sexuality as a human right, Dr. Noffsinger (chapter 3) details the legal literature, including available information on litigation. He discusses how this right is further upheld under the Americans with Disabilities Act of 1990 and explores the forensic aspects of sexuality among patients with mental illness, including competency assessments.

In tandem with respect for patient rights and privacy, hospital administrators must protect vulnerable individuals under their care and must also uphold official and social policies. In chapter 4 Dr. Buckley et al. describe these dilemmas and provide information on the management of sexual incidents and on the content of sexual policies in state facilities. The following chapter by Dr. Welch and colleagues provides a detailed account of an innovative approach to developing and implementing a policy for consensual sex among inpatients. They describe their experiences with this policy, its strengths and weaknesses that became evident upon implementation, and they offer practical suggestions for developing a successful policy.

Despite the importance of this topic, relatively little attention has been given to developing psychosexual education programs. In their chapter (chapter 6), Dr. Kopelowicz and colleagues review the literature and describe the components of a new psychosexual module they have recently developed. Their training module focuses on intimacy and sexual relationships. This chapter describes in detail how this module can be used to inform and modify sexual attitudes and practices in this patient group.

Much of the current interest in sexuality and mental illness stems from recent research on HIV risk among persons with serious mental illness. Drs. McKinnon and Cournos, leading contributors to this literature, provide a detailed account in chapter 7 of the epidemiology of HIV in persons with mental illness, its attendant risk factors and its impact upon psychiatric illness.

Dr. Rosenberg et al. (chapter 8) then address a largely underappreciated and under-researched aspect of pre-morbid development in individuals with serious mental illness. Their chapter examines the extent and implications for management of sexual trauma and revictimization in persons with serious mental illness.

In chapter 9, Dr. Milner and colleagues highlight the impact of various classes of psychotropic medications upon sexual functioning among individuals with serious mental illness. The different mechanisms that contribute to sexual dysfunction are described, with some emphasis on the pattern of dysfunction now observed with the use of novel anti-psychotic medications. Practical advice is given on interventions to ameliorate such dysfunction. From a different but complementary vantage point, Dr. McElroy et al. (chapter 10) describe contemporary pharmacological approaches to the management of

sexual deviancy and related behaviors. They apply this to current findings on the neurobiology of impulse control and sexual arousal.

The concluding chapter by Drs. Buckley and Gutheil proposes that sexuality and mental illness be conceptualized as one component of the larger topic of stigmatization of the mentally ill. They point out that, while hospital administrators struggle with upholding conflicting responsibilities in this realm, the law itself is internally consistent with respect to freedom and autonomy.

Because of its topic and diversity of chapters, it is hoped that this book will be useful to a broad audience. Clinicians of all disciplines (nursing, psychology, psychiatry, rehabilitation, social work) should find it a source of practical information and guidance in addressing this topic in everyday practice. Administrators and clinicians are provided with a full discourse on the ethical and practical complexities of developing policies sensitive to this issue. Moreover, its broader legal and social contexts are emphasized. Social scientists and interested attorneys may appreciate the breadth of review within these pages. It should also be evident that this book comes to the shelves at a time in service delivery when the rights and interests of persons with mental illness and their relatives are at a premium. It is hoped that the information contained here will be helpful to individuals and their relatives who wish to promote greater discussion of these issues.

This volume, which brings together the collective knowledge and experience of experts, reflects the current level of understanding of the complexities of sexual activity among persons with serious mental illness. The contributors are to be sincerely thanked for their insights and guidance.

CONTRIBUTORS

Peter F. Buckley, MD, Medical Director, Northcoast Behavioral Healthcare System, Northfield, Ohio; Associate Professor of Psychiatry, Case Western Reserve University, Cleveland, Ohio.

Mitch Caine, PhD, Clinical Psychologist, Los Angeles County Department of Mental Health, Los Angeles, California.

Gerrit W. Clements, BA, LLB, Special Health Consultant, Ministry of Health and Ministry Responsible for Seniors; Adjunct Professor, School of Health Information Science, Faculty of Human and Social Development, University of Victoria, British Columbia.

Francine Cournos, MD, Director, Washington Heights Community Service, New York State Psychiatric Institute, New York, New York.

Patricia E. Deegan, PhD, Director of Training and Education, National Empowerment Center, Lawrence, Massachusetts.

Timothy Florence, MD, Clinical Instructor, University of Michigan Hospital, Ann Arbor, Michigan.

Lee Friedman, PhD, Assistant Professor of Psychiatry, Case Western Reserve University, Cleveland, Ohio.

George Gintoli, MS, Chief Executive Officer, Northcoast Behavioral Healthcare System, Northfield, Ohio.

Lisa A. Goodman, PhD, Assistant Professor, Department of Psychology, University of Maryland, College Park.

Thomas G. Gutheil, MD, Professor of Psychiatry, Harvard Medical School, Boston, Massachusetts.

Michael Hogan, PhD, Director, Ohio Department of Mental Health, Columbus, Ohio.

Jodi Hyde, BA, Research Assistant, Case Western Reserve University, Cleveland, Ohio.

Paul E. Keck, Jr., MD, Professor of Psychiatry and Vice Chairman for Research, Department of Psychiatry, University of Cincinnati College of Medicine, Cincinnati, Ohio.

Alex Kopelowicz, MD, Assistant Professor of Psychiatry, School of Medicine, University of California, Los Angeles, California; Medical Director, San Fernando Mental Health Center, Mission Hills, California.

Robert G. Mangano, BS, Research Associate, Department of Psychiatry and Biobehavioral Sciences, University of California, Los Angeles, California.

Susan L. McElroy, MD, Professor of Psychiatry, University of Cincinnati, Cincinnati, Ohio.

Karen McKinnon, MA, Project Director, Columbia University HIV Mental Health Training Project, College of Physicians and Surgeons, Department of Psychiatry, Columbia University, New York, New York.

Karen Milner, MD, Clinical Assistant Professor, Director of Psychiatric Emergency Room, University of Michigan Hospital, Ann Arbor, Michigan.

Margaret E. Moreau, PhD, Senior Psychologist, Program Evaluation Services, Riverview Hospital, Port Coquitlan, British Columbia.

Kim T. Mueser, PhD, Professor, Department of Psychiatry and Community & Family Medicine, Dartmouth Medical School, Hanover, New Hampshire; Senior Research Professor, New Hampshire-Dartmouth Psychiatric Research Center, Concord and Lebanon, New Hampshire.

Stephen G. Noffsinger, MD, Director of Forensic Psychiatry, Northcoast Behavioral Healthcare System, Northfield, Ohio; Assistant Professor of Psychiatry, Case Western Reserve University, Cleveland, Ohio.

Tricia Robben, BA, Research Assistant, Case Western Reserve University, Cleveland, Ohio.

Stanley D. Rosenberg, PhD, Professor of Psychiatry, Dartmouth Medical School, Lebanon, New Hampshire.

Cesar A. Soutullo, MD, Child and Adolescent Psychiatry Fellow, Division of Child and Adolescent Psychiatry and Biological Psychiatry Program, Department of Psychiatry, University of Cincinnati College of Medicine, Cincinnati, Ohio.

Dale P. Svendsen, MD, Medical Director, Ohio Department of Mental Health, Columbus, Ohio.

Rajiv Tandon, MD, Associate Professor of Psychiatry, University of Michigan, Ann Arbor, Michigan.

Kim M. Thompson, MA, Graduate Assistant II, Department of Psychology, University of Maryland, College Park.

Oladapo Tomori, MD, Clinical Instructor, University of Michigan, Ann Arbor, Michigan.

Steven J. Welch, PhD, Chairperson of the Taskforce on Patient Sexuality, Department of Psychology, Riverview Hospital, Port Coquitlan, British Columbia.

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Sexual Behavior in Persons with Serious Mental Illness: Patterns and Clinical Correlates

PETER F. BUCKLEY, TRICIA ROBBEN, LEE FRIEDMAN and JODI HYDE

The sexual practices of persons with serious mental illness raise important clinical, social and legal concerns. Yet, in spite of the seriousness of this topic, there is relatively little systematic information on the extent and pattern of sexual activity in this population. This chapter provides an account of the current knowledge of this issue viewed in the context of normative sexual practices in the population at large and sexual activity among patients with other psychiatric disorders.

Normative Sexual Practices

Few aspects of human activity evoke the interest of the media and popular press as much as sexuality. We are bombarded with television and magazine reports of sexual interests, preferences, and lifestyles in the 1990s. However, surprisingly, and in contrast to this voluminous lay literature, epidemiological research on the normative expression of sexuality is relatively scant. Such information is important and is required to inform and guide public health policy regarding HIV infection and other sexually transmitted diseases. Epidemiological information on sexuality in the general population is also of direct importance to psychiatry as it provides the backdrop to

evaluating sexual impulsivity, sexual deviancy, sexual dysfunction and sexuality in clinical practice.

Several, well-conducted epidemiological surveys have recently addressed this issue. In a British random-sample survey of 18,876 males and females (age range 16–59) that was conducted during 1990–1991 (Johnson *et al.*, 1992), it was observed that 8.2% of males and 4.8% of females reported having 2 or more heterosexual partners in the previous year. Sexual activity was increased among those who were unmarried, of higher social class, and who had first intercourse before age 16. While just over 60% of males reported any lifetime homosexual experience, 3.6% of males had a current homosexual partner. Results from a French study broadly endorsed these findings and emphasized that only 59% of males had used condoms in the last year (ACSF, 1992). The median age at first intercourse was 17 years for men and 18 years for women. Lifetime rates of homosexual intercourse were recorded at 4.1% for males and 2.6% for females, although the majority (approximately 80%) of these people had bisexual experiences. Seidman and Reider (1994) conducted a comprehensive review of epidemiological data on human sexuality collected from several American public health surveys. Their findings are summarized in Table 1.1. In brief, they highlighted that the overwhelming majority of adolescents are sexually active by age 19. Adolescents experience multiple, serial sexual relationships. Young adults show a similar pattern, while older adults tend towards monogamy and a declining frequency of sexual activity. Although estimates vary, some 3% of males are exclusively homosexual and a similar percentage have bisexual practices (Seidman and Reider, 1994).

Assessment of Sexual Behavior

As stated above, sexual preferences and practices are highly personal and emotive issues. There is no simple or best manner to assess sexual practices among persons with mental illness. Approaches to assessing sexual behavior vary widely, both in their sensitivity and degree of intrusion upon patient privacy (see Table 1.2). Approaches used in studies of sexual behavior among persons with serious mental illness are highlighted in Tables 1.3 and 1.4.

Sexual attitudes may be explored by way of self-report questionnaires. These have the advantage of being minimally intrusive and, accordingly, may encourage candid disclosure of personal information. However, these questionnaires are difficult to construct and require the use of language that is clear and neutral. Also, they must avoid being either too technical (vivid descriptions may be offensive) or overly-vernacular. Also, information derived from a self-report questionnaire may be unreliable and is open to all the vicissitudes of survey research (Johnson *et al.*, 1992); this is compounded by the

Table 1.1. Representative Data on Sexual Activity Among American Men and Women.[1,2,3]

	% Sexually Active	2 or More Partners	Frequency of Intercourse
Aged 15-19			
Females	66% - 75%	46%	39.5% females, 53.5% males had sex during the preceding 3 months
Males	79% - 86%	40.5%	
Aged 19-24			
Females	81%	31%	35% females, 28% males had intercourse more than 10 times a month
Males	84%	56%	
Aged 25+			
Females	- - -	66%	58% females, 43% males had intercourse more than once a week
Males	91%	80%	

[1]Data derived from several epidemiological studies - see Seidman and Reider (1994).
[2]Sexual activity refers to heterosexual intercourse.
[3]1-6% males engaged in homosexual activity; data for females was not given.

possible influences of psychiatric symptoms and cognitive impairment. Review of clinical records is perhaps the least intrusive approach but this is of most dubious value since clinicians rarely document (at all) the sexual experiences of inpatients. Inquiring staff directly about their observations of the sexual behavior of patients is an approach best used as a collateral rather than primary source of information. It is difficult to obtain detailed information from staff and they may be genuinely unaware of the patient's lifestyle in the community. Moreover, the information is likely to be influenced by that individual's sexual attitudes. On the other hand, collateral history from staff can be of great assistance in instances of alleged sexual assault between inpatients or when a psychotic patient with sexual preoccupations makes an erroneous allegation of sexual misconduct by staff on the unit.

Clinical assessment of patients requires attention to their sexual history. However, this aspect of the psychiatric evaluation is underemphasized and clinicians frequently obtain (at best) only superficial and cursory information. This point is well emphasized in other chapters in this book. More recent studies of high-risk sexual behavior among persons with serious mental illness (see Tables 1.3

Table 1.2. Approaches to the Assessment for Sexual Behavior Among Mentally Ill Patients.

Method	Strengths	Weaknesses
Self-report	protects privacy; may allow for individual comments; brief	reliability unknown without collateral; patient may be confused and misinterpret information
Medical chart review	not intrusive, combines patient report and (multiple) staff observations	sexual histories often incomplete; staff rarely document sexual behavior
Staff observation/ questionnaire	direct observation; not intrusive to patient	staff perceptions may be inaccurate; personal mores may bias data
Patient interview	source information; may access sensitive issues	patient may not disclose personal information; clinicians may be unskilled in questioning sexual matters
Structure patient interview/ questionnaire	more detailed information scale may have established reliability	may be too detailed to administer; time consuming
Patient physical examination	objective; of medicolegal importance	intrusive; rarely appropriate; information obtained may not be specific
Laboratory testing - semen testing - STD testing - HIV testing	objective; useful in prevention of spread/minimizing risk to population	intrusive; major ethical considerations

Table 1.3. Representative Studies of Sexual Activity in Patients with Schizophrenia.

	Assessment Method	Period of Observation	Patient/ Control Sample	Site	Sexually Active	Sexual Relations Comments
Akhtar (77)	SI	two years	34	inpatient	3.1%	94% of encounters were heterosexual
Modestin (81)	observation	one year	16	inpatient	1.5%	100% heterosexual of sexual activity
Lyketsos (83)	PQ	inpatient	113/106	inpatient	N.S.	87% males, 42% females had sexual dysfunction associated with psychotropic meds
Friedman (84)	SQ, SSPI	life time	20/15	community	N.S.	60% female patients (13.4% controls) never experienced orgasm
Rozensky (84)	PQ	life time	61	community	80%	18.5 mean age at first intercourse; 16% homosexual
Raboch (86)	SPI	six years	20/101	community	N.S.	slower sexual development among female patients (versus controls)
Baker (91)	SPI	one year	23	community	78%	57% of adolescent females reported high-risk sexual behaviors
Kelly (92)	PQ	one year	60	community	62%	42% males, 19% females had multiple partners/infrequent condom use
Volvaka (92)	PQ	one year	476	community	N.S.	14.4% high-risk patients HIV positive
Cournos (93)	SPI	six months	95	community	57.8%	9.8% patients use condoms; 18.5% patients had homosexual experiences
Diclemente (93)	SPI	15 months	76/802	community	53%	mean age of first intercourse = 11.4 years; 20% had homosexual experience
Cournos (94)	SPI	six months	95	community	44%	22% had some (lifetime) homosexual experience

Table 1.3. (Continued)

	Assessment Method	Period of Observation	Patient/ Control Sample	Site	Sexually Active	Sexual Relations Comments
Kalichman (94)	SPI	one year	95	community	54%	18% received drugs/money for sex; 27% had multiple partners
McDermott (94)	PQ, SPI	six months	61/32	community	N.S.	22% had homosexual experience; psychiatric patients frequency of intercourse for a month is similar (9.5 times versus 9.8 control subjects)
Susser (95)	SSPI	two years	122	community	53%	86% heterosexuals; 30.7% homosexuals (includes bisexuals); half of sexually active men didn't use a condom with a non-monogamous partner
Chuang (96)	PQ	one year	151	community	51.7%	25% thought one unsafe sexual contact would not have them vulnerable to AIDS; 33% do not insist on condom use
Coverdale (97)	PQ	one year	66/66	community	55.4%	patients were more likely than controls to have coerced sex

PQ = patient questionnaire
SQ = staff questionnaire
SI = staff interview
SSPI = semi-structured interview
SPI = structured patient interview
N.S. = not specified

Table 1.4. Representative Studies that Detail the Pattern of Sexual Activity Among Patients with Serious Mental Illness.

	Sexually Active	Relationships Monog/Multiple		Sex in Exchange for Money/Goods	Use of Contraception	Alcohol/Drug Abuse	Treatment for STD's	Masturbation
Rozensky (84)	80%	N.S.	N.S.	N.S.	23%	N.S.	N.S.	88%
Baker (91)	78%	N.S.	N.S.	N.S.	17%	30%	17%	N.S.
Kelly (92)	62%	N.S.	42%m 19%f	13% N.S.	15%	91%	33%	N.S.
Cournos (93)	57.8%	55.4%	44.6%	N.S.	9.8%	N.S.	N.S.	N.S.
Diclemente (93)	53%	38%	N.S.	15%	23%	9%	15%	N.S.
Cournos (94)	44%	38%	62%	50%	9.8%	45%	N.S.	N.S.
Kalichman (94)	54%	N.S.	27%	18%	24%	<50%	32%	N.S.
Susser (95)	53%	N.S.	21%	25%	24%	65%	N.S.	N.S.
Chaung (96)	51.7%	N.S.	17.4%	6.7%	N.S.	N.S.	5.4%	N.S.
Coverdale (87)	55.4%	N.S.	36.4%	2.9%	N.S.	N.S.	18%	N.S.

N.S. = Not Specified

and 1.4) demonstrate that is possible through careful interviewing to elicit reliable information on sensitive, sexual details. Moreover, once questions are appropriately phrased, persons with mental illness do not mind (and in fact anticipate) being questioned about intimacy (Crawford and Shaw, 1998; also see Deegan, this volume). The quality of information is dependent upon the frankness of the patient, the context of the assessment, the quality of the therapeutic alliance, and the skill of the clinician. For research purposes, the use of structured interviews can help to provide more direct and exact information on sexual practices in a manner that is reproducible and quantifiable across different studies. Several useful scales have been published. Volavka and colleagues (1992) also reported good reliability for a 13-item screening questionnaire, the Risk Behavior Questionnaire. Burke and colleagues (1994) described a structured interview to evaluate sexual function in male patients with schizophrenia. Carmen and Brady (1990) have described a checklist for assessing sexual history and risk of HIV. Several other studies cited in Tables 1.3 and 1.4 used other questionnaires developed to assess patient sexuality (details on specific questions are not given but the primary authors indicate that the scale is available upon request).

Finally, physical examination and relevant testing may be appropriate and helpful in a minority of cases (e.g., when medicolegal concerns arise; [also see Noffsinger, this volume]). Examinations should be performed (after appropriate consent is obtained) by a physician other than the attending psychiatrist. HIV testing is another important component of the patient evaluation, although such testing is fraught with serious ethical considerations (Grassi, 1996).

Accurate detection of sexual behavior among patients may be enhanced by staff who are appropriately trained to assess and manage this issue. This is a generally neglected area for staff training. Staff are often bewildered when confronted with issues of patient sexuality (Mossman *et al.*, 1997). Staff may have inconsistent and ill-formed personal values regarding sexuality and they differ widely in their level of knowledge about human sexuality and its health consequences (Civic *et al.*, 1993). Staff require explicit information and training about aspects of sexuality and their implications for care of psychiatric patients. Staff need to learn how to take a detailed sexual history and elicit personal details in a non-threatening, open manner. Such training should occur early in the health professional's career since this will emphasize its importance and counter historical misconceptions. At present, medical students and residents are not taught a format for acquiring information on sexual activity.

Misconceptions Regarding Sex and Serious Mental Illness

The stereotypic impression is that persons with serious mental illness are either asexual or have bizarre sexual experiences. The former

impression was supported by earlier studies showing a very low rate of sexual activity among patients. For example, Modestin found only 9 instances of sexual intercourse over a one year period by 16 of 1,060 patients (Modestin, 1981). Similarly, Akhtar and colleagues could only identify 34 of 1,120 inpatients who had been 'sexually explicit' (defined as intercourse, masturbation, or fondling) during a 2-year period (Akhtar *et al.*, 1977). Reports of sexuality among inpatients were uncommon and the prevailing attitude (even more than today) was to dismiss the issue and conclude that persons with serious mental illness were incapable of meaningful sexual relationships. At the same time, evidence of patient sexuality was viewed in psychodynamic terms: "the onset of schizophrenia often causes a release of sexual impulses, experienced initially as obsessional urges, preoccupations and vague bodily sensations. This upsurge often results in delusions, elaborate hallucinatory phenomena, and sexual acting out. The form such release takes varies with the individual's psychodynamic constellation, as well as the degree of regression" (Akhtar and Thompson, 1980). Sexual aberrancy was closely equated to mental disturbance: "self-induced genital injury and autocastration are almost pathognomonic of schizophrenia" (Akhtar and Thompson, 1980). Moreover, it was hypothesized that sexual excesses, masturbation and bizarre activities could induce psychosis (Nesteros *et al.*, 1981). In a survey of U.S. psychiatrists and patients (Pinderhughes *et al.*, 1972), 66% of psychiatrists considered sexual activity a contributory factor to psychosis. Thirty-three percent of psychiatrists and a similar number of patients believed that sexual activity was detrimental to recovery from mental illness. Nesteros and colleagues (1981) conducted an extensive literature search which revealed only four clinical studies published between 1966 and 1980. In their own study (Nesteros *et al.*, 1981), they reported that only eight percent of male patients were sexually active before the onset of their illness and only two percent in the year prior to the survey (compared with 58% of control subjects); heterosexual and autoerotic (masturbatory) activity predominated. Fourteen percent of patients reported that they had never engaged in any kind of sexual activity or ideation. Additionally, 22% of patients reported impotence, 19% had retarded ejaculation and 32% were unable to ejaculate.

The term "neglect and psychiatrization" was coined to describe the response of professionals to sexuality among persons with mental illness (Vandereycken, 1993). Psychiatrists infrequently inquire about sexual side-effects of medication in their patients, implying that this is an unimportant concern. Patients' sexual lives were considered disturbed and should be a treatable consequence of their mental disorder. Vandereycken argued that professional staff were confused by patient sexuality and that their medicalized stance thereby avoided confronting the issue. This point is further emphasized in the chapter by Dr. Deegan in this book.

More recent prevalence studies estimating sexual activity among persons with serious mental illness vary widely depending upon the