

An Observational Study of Sexual Behavior in Demented Male Patients

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Background. Concerns have been expressed that patients with dementia will display disinhibited, inappropriate sexual behavior. Retrospective research suggests that this is rare, but no observational research has been reported. The purpose of this study was to conduct such an observational study.

Methods. Subjects were 40 patients with a dementia diagnosis who were living in institutional settings; subjects ranged in age from 60 to 98. Coders observed subjects on nine separate occasions, three in the morning, three in the afternoon, and three in the evening. Subjects were observed in multiple situations; coding included appropriate, ambiguous, and inappropriate sexual behaviors. Reliability coding was obtained for 42% of the patients on 11% of coded episodes.

Results. Behaviors could be coded with high reliability (94% to 100% across categories of behavior). On average, patients displayed .43 appropriate sexual behaviors, 1.48 ambiguous behaviors, and .83 inappropriate behaviors across the nine observation periods. This was not evenly distributed across patients, however; only 18% of patients ever displayed a sexually inappropriate behavior, and these were usually brief and minor. Inappropriate sexual behavior was observed in only 1.6% of the observed one-minute time segments.

Conclusions. Observational research documents what had been previously suggested by retrospective reports: inappropriate sexual behavior is uncommon in dementia patients and brief and minor even when it occurs. Ambiguous behaviors, such as appearing in public incompletely dressed, which could suggest exhibitionism but more likely reflects self-care deficits, were more common. Misinterpretation of these events may be the source for some of the persistent lore regarding sexually disinhibited behavior in dementia patients.

CONCERNS that patients with Alzheimer's disease will display inappropriate sexual behavior are frequently voiced in lay and professional literature. For example, Mace and Rabins (1) report: "One wife who brought her husband to the hospital for care confessed that she had no problems managing him but that she had been told that, as he got worse, he would go into his 'second childhood and start exposing himself to little girls'" (p. 101).

Despite these concerns, the available research suggests a different conclusion. Bozzola et al. (2), using personality, interests, and behavior items from the Blessed Dementia Scale to assess personality change in 80 patients with Senile Dementia of the Alzheimer's Type (SDAT), found that the least frequent personality change was "sexual misdemeanor" (3.8%). Similarly, Burns, Jacoby, and Levy (3), utilizing the Stockton Geriatric Rating Scale (4) to assess behavior disturbance in 178 patients with SDAT, reported sexual disinhibition in 7% of subjects. Rabins and colleagues (5) interviewed the primary caregivers of 55 patients suffering from irreversible dementia and found that only one family reported the occurrence of inappropriate sexual behavior. Kumar et al. (6) compared data, obtained from questionnaires, for 28 SDAT patients and normal controls. No significant difference in the incidence of assaultive and sexually inappropriate behavior was noted between the groups. Thus, all available data present low rates of sexually inappropriate behavior. However, there are two important limitations to these data.

First, no direct observational data were reported in this literature; all studies relied on retrospective reports from family members or staff providing patient care. This methodology depends on accurate reports from memory regarding the patient's behavior. Second, no studies carefully distinguished among different kinds of sexual behavior. Inappropriate and appropriate sexual behavior are not differentiated; in some studies any overt indication of sexual interest would likely be coded as inappropriate. We have argued in other reports for the importance of considering the appropriate role of sexuality in SDAT patients and their spouses or partners (7). For example, touching one's partner's breast in public is inappropriate, but touching it in private is not. Although not inappropriate, it may be upsetting to a caregiver who is no longer interested in sexuality, so the caregiver may incorrectly label it as inappropriate. In addition, earlier studies have not carefully distinguished inappropriate nonsexual versus sexual behavior. For example, behavior may be incorrectly labeled "sexual" when a demented patient goes out with his fly unzipped and genitals partly exposed. However, this usually is not exhibitionism, but simply a consequence of poor cognitive function and inability to carry out personal care, such as dressing oneself. True sexually inappropriate behavior consists of overt acts with a sexual meaning.

Our goal was to conduct an observational study of sexual behavior in patients with SDAT and other dementing conditions. Behavior to be observed distinguished three categories

ries: sexually appropriate behavior (e.g., kissing one's spouse), sexually ambiguous behavior (e.g., having genitals exposed, which could be purposeful or because of incomplete dressing), and sexually inappropriate behavior (e.g., publicly masturbating).

Hypotheses to be tested were: (a) A low incidence of all sexual behaviors will be found, and (b) Sexually ambiguous behavior will occur more frequently than inappropriate behavior. In addition, we planned to compare behavior in patients with SDAT vs other dementing conditions, to determine whether patients with other disorders would display more or less sexually inappropriate behavior and whether there would be qualitative differences in the types of sexual behavior occurring with different dementing conditions. No data were available on which to base specific predictions.

METHOD

Subjects

Subjects were 40 male patients diagnosed with dementing illness, living in one of three long-term care facilities at the Palo Alto VA Medical Center. Patients ranged from 60 to 98 years old and had been in institutional care for 6 months to 8 years. Twenty-two patients (55%) had a diagnosis of SDAT; 18 (45%) had diagnoses of other dementing conditions (multi-infarct dementia, Korsakoff's syndrome, Pick's disease). Diagnoses based on DSM-III-R criteria were available for nine SDAT patients who were followed by a longitudinal Alzheimer's research project, with subsequent autopsy confirmation for six of these patients. Of non-SDAT patients, three had also been followed by the same research team; two had subsequent autopsy confirmation of diagnoses. The remaining dementia patients were only included if chart review showed adequate testing and historical evidence consistent with the recorded probable diagnosis, based on DSM-III-R criteria (8). Informed consent for participation in the study was obtained from the person holding power of attorney or conservatorship of the patient.

Patients on the units observed did not have medical illness, other than the dementing condition, severe enough to require care in a more intensive medical setting. For patients with acute infectious illness (e.g., a bladder infection), data collection was postponed until after recovery. Chart reviews on all patients provided concurrent medical diagnoses and medications. Most patients had no major medical problems; 10 patients did have another diagnosis, most commonly hypertension, thyroid disorder, or glaucoma. Most (31 of the 40) were on no medications other than psychoactive medications (e.g., Haldol, Buspar); 23 were taking at least one psychoactive medication.

Coding

Coders were three research assistants in a project devoted to SDAT research. They were familiar with dementing conditions and research protocols, but not with specific hypotheses being tested. Coders received training on the observational procedures (described below) using patients who were not included in the analyses. Coders were trained by one of the authors (AMZ), to a criterion of exact correspondence to her coding before recording data for this project. The coder positioned him- or herself where he could

see the patient clearly, but the patient was not aware of being observed. Coders did not interact with subjects or other patients beyond brief pleasantries.

Each subject's behavior was coded continuously for 5 minutes on each of nine occasions on a standardized coding sheet, one minute of observation per line. Any instances of codable behavior (defined below) were entered. When no codable behavior occurred, brief descriptive commentary was entered, indicating what occurred and the subject's general behavior (e.g., "sitting quietly, staff member approaching"). For each codable behavior, coders also wrote brief commentary to indicate the behavior of others in the vicinity; commentaries were used to examine antecedents and consequences of behavior. Antecedents were not coded in a standardized format, but were examined to see who was interacting with the subject, if anyone, and any noteworthy events prior to the codable behavior. Consequences were coded as positive (e.g., patient receives praise or attention), negative (e.g., patient is criticized or avoided), neutral (e.g., staff comment calmly on patient's behavior), or no response (e.g., staff appear not to notice patient's behavior).

Behaviors coded. — Three categories were coded: appropriate, inappropriate, and ambiguous sexual behaviors. Behaviors considered inappropriate were: making explicit sexual comments, touching someone other than partner on breast or genitals, touching partner on breast or genitals in public, exposing breasts or genitals in public. Behavior codes that were usually considered ambiguous were: being undressed outside the bedroom or bathroom, rubbing up against another, and touching self on breasts or genitals in public. The hardest coding task was differentiating ambiguous from clearly inappropriate behavior in the "generally ambiguous" categories. For example, sitting with one's hands in lap cupped over genitals was considered ambiguous. However, if hands were moving in a masturbatory pattern it was coded as inappropriate. Since our hypothesis was that behaviors would be infrequent, we used the ground rule, "When in doubt, code it inappropriate;" i.e., we attempted to err on the side of *not* supporting our hypotheses. Reliability checks included distinguishing inappropriate from ambiguous behaviors. Behaviors coded as appropriate were sitting close to someone (with arms or legs touching), kissing, and stroking someone on the face, hands, or arms.

Reliability coding. — Reliability coding was done by one of the authors (AMZ). Coders stood together and coordinated timing for beginning, line changes at the end of each minute, and ending, but otherwise did not interact during coding. Percent of exact matches in coded behavior were calculated, overall and for the appropriate, inappropriate, and ambiguous distinctions. If a reliability coding session showed discrepancies, coders participated in a recalibration session: they observed a nonactive subject, discussed codes, and worked out disagreements, ensuring that coders maintained identical criteria. Recalibration observations were not used in analyses.

Number of observations. — Each subject was coded nine times (three times each in the morning, afternoon, and

evening). Patients were observed in different situations such as being in the day room, at meals, being groomed or dressed, in their rooms, and any other standard situation on the unit. The three observations within each time period were on different days. We attempted to do each of the nine coding sessions on a different day, but some patients were coded once in the morning, once in the afternoon, and/or once in the evening on the same day.

RESULTS

Reliability

Seventeen subjects (43%) were observed by two coders simultaneously at least once; 41 intervals were coded (11%). Using the reliability coder as criterion, exact matches were obtained for 100% of appropriate behaviors, 100% of "no sexual behavior," 95% of inappropriate behaviors, and 94% of ambiguous behaviors.

Frequency and Duration of Sexual Behavior

The first hypothesis predicted a low frequency of sexual behavior of any kind. The mean number of observed behaviors across the total 45 minutes of observation for each patient appear in Table 1; data support the hypothesis. For example, over 45 minutes, spread across nine periods of observation, less than one inappropriate behavior was observed per SDAT patient on average. Appropriate sexual behavior was even less common, for both SDAT patients and patients with other dementing diagnoses. Ambiguous behaviors were somewhat more common, although still infrequent. In addition, we calculated the percent of patients who ever displayed sexual behavior, since behaviors were not evenly distributed among patients. Those percentages and the actual number of patients they represent are shown in Table 2, and they indicate even more clearly that sexual behavior, whether appropriate or inappropriate, was uncommon. Only two patients (9%) with a diagnosis of SDAT ever displayed sexually inappropriate behavior during the observation period.

Finally, we examined what amount of the observation time was taken up with sexual behaviors. We cannot report an exact length of time, but can report based on the number of minute-long segments, within the 45 observed for each patient, which included sexual activity. Here the figures show an even lower amount of activity. Of the 1,800 time segments coded, inappropriate behavior occurred in 27, or 1.6%, and ambiguous behavior occurred in 67, or 3.7%.

To examine the relationship of length of time in the long-term care setting to likelihood of sexual behavior, the sample was divided at the median into those with stays of zero to two years versus those with stays of three or more years. For each group, the number of patients ever displaying inappropriate behavior and ambiguous behavior was examined in separate chi-square analyses and found to be nonsignificant ($\chi^2 < 1$, n.s. for both inappropriate and ambiguous behavior). Similarly, patients were divided into those on psychoactive medication and those not on psychoactive medication; this variable was not related to presence or absence of sexually inappropriate or ambiguous behavior ($\chi^2 < 1$, n.s., for both).

Table 1. Mean Frequency of Occurrence of Sexual Behavior Across All Observations

Type of Behavior	SDAT Diagnosis <i>n</i> = 22	Other Diagnosis <i>n</i> = 18	Overall <i>n</i> = 40
Appropriate behaviors	.55	.28	.43
Inappropriate behaviors	.68	1.00	.83
Ambiguous behaviors	1.50	1.44	1.48
Inappropriate + ambiguous behaviors	2.18	2.44	2.30

Table 2. Percent of Patients Ever Displaying Sexual Behavior During Observation Period*

Type of Behavior	SDAT Diagnosis <i>n</i> = 22	Other Diagnosis <i>n</i> = 18	Overall <i>n</i> = 40
Appropriate behaviors	18% (4)	22% (4)	20% (8)
Inappropriate behaviors	9% (2)	28% (5)	18% (7)
Ambiguous behaviors	23% (5)	33% (6)	28% (11)
Inappropriate + ambiguous behaviors	23% (5)	50% (9)	35% (14)

*Actual number of patients shown in parentheses.

Relative Frequency of Different Types of Sexual Behavior

The second hypothesis predicted that ambiguous behavior would be observed more frequently than inappropriate behavior; means appear in Tables 1 and 2. Two methods for testing the statistical significance of these differences were used. First, the distribution of subjects in each of four cells was compared: those displaying ambiguous behavior and inappropriate behavior ($n = 5$), those displaying ambiguous behavior but no inappropriate behavior ($n = 6$), those displaying inappropriate behavior but no ambiguous behavior ($n = 3$), and those displaying neither behavior ($n = 26$). The chi-square value was significant ($\chi^2 = 6.14$, $p < .02$), indicating that cell values are not randomly distributed. However, since this could be due to the preponderance of subjects displaying neither behavior, the *t*-test procedure was also used, including only subjects who ever displayed sexual behavior ($n = 14$). For each subject, the difference between frequency of ambiguous and inappropriate behaviors was calculated and tested against the null hypothesis that each would occur at equal frequency. Results supported our hypothesis: ambiguous behaviors were significantly more frequent than inappropriate behaviors ($t = 2.43$, $p < .001$).

SDAT Patients vs Patients With Other Dementing Conditions

We were interested in whether sexual behavior would be quantitatively or qualitatively different for patients with SDAT versus other dementing conditions. Tables 1 and 2 suggest that SDAT patients have lower frequencies of inap-

appropriate and ambiguous behavior and higher frequencies of appropriate behaviors. However, chi-square analyses showed no significant differences, looking at the number of patients who ever displayed sexually appropriate behavior, ambiguous behavior, inappropriate behavior, or the combination of inappropriate and ambiguous behavior across the two groups. We also conducted *t*-tests comparable to those described above, i.e., utilizing only patients who ever displayed sexual behavior. These tested the mean occurrence of each type of behavior, comparing SDAT to other dementing conditions. These *t*-tests were not significant for occurrence of appropriate, inappropriate, ambiguous, or the combination of ambiguous and inappropriate behavior.

When the number of time segments involving sexual activity in each group was examined, a nonsignificant difference between the two groups was also found, but again in the direction of more inappropriate behavior for patients with non-SDAT dementias. Of the two men with SDAT diagnoses who ever displayed inappropriate behavior, only 3 of 45 observational segments for the first patient and 9 of 45 coding segments for the second included inappropriate behavior. Thus, of the 990 minute-long segments coded for SDAT patients, only 1% (12 segments) included any inappropriate sexual behavior. For patients with other dementia diagnoses, 17 segments, or 2% of all segments observed, included inappropriate sexual behavior (for the 5 patients who ever displayed inappropriate behavior, the number of segments was 1, 10, 3, 1, and 2). With regard to ambiguous behavior, the numbers were, of course, higher. For patients with SDAT diagnoses, of the 5 who ever displayed ambiguous behavior, the number of segments involved ranged from 5 to 12 (specifically, 5, 6, 6, 11, and 12). Of the 990 segments for all SDAT patients, this represents a total of 40 (4%) involving sexually ambiguous behavior. For patients with other dementia diagnoses, of the six who ever displayed ambiguous behavior, number of time segments involved ranged from 1 to 13 (1, 1, 2, 4, 6, 13). Thus, ambiguous sexual behaviors were observed in 3% of the time segments for this group.

Although the frequency data showed no significant differences, there were qualitative differences between the behavior observed in SDAT patients compared to some patients with other dementing conditions (examples shown in Table 3). Inappropriate behaviors coded for SDAT patients were generally brief genital rubbing, with apparent unawareness that the behavior might be observed. Inappropriate behav-

iors coded for other patients were more provocative, with apparent awareness of audience and more extensive masturbatory behavior.

In addition, there were some qualitative differences in antecedents. (We had originally intended to use quantitative data analytic techniques with the observations of antecedents. However, because sexual behaviors were so infrequent, there are not enough data points to examine differences among types of antecedents to different sexual behaviors. Therefore, only qualitative analyses are reported for antecedents.) SDAT patients seemed to display inappropriate behavior when agitated and restless, or when there was some other potential cause of genital area discomfort, such as constipation. The behavior of patients with other dementing diagnoses typically had no apparent, codable antecedents; the behavior appeared in a previously quiet patient, perhaps as a response to boredom or a desire for attention.

Responses to Sexual Behavior

We originally coded responses of staff, other patients, and/or visiting family members into positive, neutral, negative, and ignoring; we intended to examine responses to different behaviors. Coding responses was easy: all but seven behaviors were ignored (100% coding reliability). Five behaviors which brought responses were appropriate, e.g., patients taking a staff member's hand; all responses to these behaviors were positive. One staff member also responded to a patient's ambiguous behavior (pants slipping off because they were unfastened) with a neutral response. Specifically, she said, "He's losing his drawers" and started toward him, but got distracted and did not complete the interaction. No staff member responded to inappropriate behavior, although on the most blatant example observed of inappropriate behavior (a patient disrobing on the unit and masturbating while extremely agitated) another patient did respond negatively: "What the hell are you doing?" This covered staff on three shifts, engaging in a variety of tasks with patients. This may be a result of the fact that none of the inappropriate behaviors were directed specifically at staff or another patient, thus requiring a response. In fairness, staff on the units observed were not generally unresponsive to patients. They provided a high level of care and were interactive with patients during daily activities and planned recreational opportunities. They just generally did not re-

Table 3. Qualitative Data From Observation of Sexual Behavior

	SDAT Diagnosis	Other Dementing Diagnosis
Inappropriate behaviors	S5 Hand clutches groin area (no movement)	S12 Masturbation in public (obviously seen)
	S17 Rubs genitals briefly	S28 Hand to groin, rubbing
		S36 Masturbation in public (obviously seen)
Antecedents	S5 Agitated, restless patient with constipation	S12 No immediate antecedent
	S17 Patient accidentally left in bathroom unattended; very agitated when found and brought out to dayroom	S28 No immediate antecedent
		S36 No immediate antecedent; no response to wife's touch earlier, but later obvious masturbation

spond to sexual behavior, although they responded positively when patients initiated appropriate touch.

DISCUSSION

This research, using observational methodology, confirms what prior survey research suggested: patients with dementia diagnoses display little sexually inappropriate behavior. In addition, this observational research shows that very little sexual behavior of any kind is displayed by these patients. Examining mean frequency, positive, appropriate sexual behaviors were even less frequent than ambiguous or inappropriate behaviors. An almost identical proportion of patients were observed displaying appropriate behavior compared to inappropriate behavior.

Reliably distinguishing sexually ambiguous behaviors from inappropriate behaviors was possible, although training was necessary to learn this differentiation. Most ambiguous behavior consists of actions that violate body privacy norms for nondemented patients (e.g., walking around with pants unzipped, scratching oneself on the genitals in public), but which do not seem to be expressing or fulfilling a sexual need. Staff on care units for dementia patients might benefit from training in making these distinctions, in order to reduce their discomfort with perceived sexual activity. Family members also might benefit from similar training.

The data also suggest that staff on special care units might benefit from training on responding calmly to sexually ambiguous behaviors and, especially, to the infrequent instances of inappropriate behavior. Staff on the units we observed may not be completely representative, but they were caring, committed personnel, with good basic training in working with dementia patients. Nonetheless, they did not respond to sexual behavior, even on the rare instances when it was blatant and upsetting to other patients. Training in recognizing sexual behavior early in a sequence, learning strategies to handle the behavior, and developing ways to encourage appropriate touch and sexual pleasure could be helpful to staff, patients they care for, and family visitors.

Although there were no significant mean differences in types of behavior across dementing conditions, the qualitative data suggest possibilities worth exploring in further research. Some patients with dementia due to causes other than SDAT displayed more purposeful sexual behavior, compared to the more passive, oblivious behaviors seen in the SDAT patients. Adding additional categories to the behavioral coding and generating samples with large numbers of patients representing each of several dementia diagnoses would be helpful in documenting these differences. For example, patients with alcohol-related dementias or brain lesions localized in certain areas may display more

inappropriate behavior. While beyond the scope of this project, obtaining such samples could provide useful future information.

Although we have argued that these results suggest a low likelihood that demented patients will create sexual disturbance, there is a subjective quality concerning what should be considered a "low rate" of behavior. It could be argued that the 18% of patients who displayed at least one inappropriate behavior during the observation period is actually a high number; we might expect a lower rate if we were observing a roomful of healthy, cognitively intact older men. It is important to keep in mind, however, that the data indicate that these were generally fleeting events, not the kinds of behaviors suggested by the idea that dementia patients might enter "a second childhood." Some inhibition seems to be lost with dementia, and the result is that patients occasionally touch themselves with less concern for privacy. Dementia, at least in this observational study, never resulted in sexually aggressive behaviors toward staff or other patients, and it rarely resulted in behavior that showed any evidence of meeting a specifically sexual purpose (such as sexual gratification). It is time to lay to rest fears of rampant disinhibited behavior from demented patients. We urge that the field turn instead to developing our understanding of how to help staff and families deal with the mild problems that can occasionally occur and to efforts which support the right of demented patients to appropriate sexual gratification.

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