Denial: Implications of a Pilot Study on Activity Level Related to Sexual Competence in Burned Adults

(adaptation, psychological; defense mechanism; occupational therapy)

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The purpose of this pilot study was to explore the effect of disfigurement on sexual competence and the relationship between self-reported activity level and sexual competence in burned-disfigured adults. Because of a small sample size and methodological limitations, findings were intended to be informative for planning further research rather than definitive. Results showed a strong positive correlation between activity level and sexual competence. Additional findings showed surprisingly high activity levels reported by subjects who were greatly disfigured. It was speculated that denial may have affected the results of this study. Based on this, the clinical implications of denial were explored, and suggestions for future research were generated.

This pilot study was conducted to determine what, if any, relationship existed between self-reported activity level and sexual competence in burn-disfigured adults. Activity level, defined as confidence in participation in activities of daily living (ADL) and school/vocational, home chore, cognitive problem solving, social-recreational, and community mobility events, is a long-standing area of concern for occupational therapists (1). In contrast, sexual competence, defined as the ability to interact comfortably with others in terms of the sex drive and sexual acts, is a more recently recognized area of interest within the field of occupational therapy (2-4).

Physical disfigurement is often equated with ugliness (5). As burned persons confront this problem, they may feel that their disfigurement has rendered them no longer lovable (6), particularly since it often leads to expressions of revulsion from strangers (7). Such responses reinforce burned persons' feelings of loss of lovability and may therefore have serious social implications.

Body image is defined by Simon (8) as including "not only the individual's personal investment in his body, but the views, values, and fantasies of the other significant people in his environment, and the attitudes and values of the culture" (p 408). Body image and self-identity, interrelated elements that are components of self-acceptance, are strongly affected by the responses of others (9). If burn-disfigured persons receive negative reactions from others, they may become convinced that they do not look attractive and may even decide they feel unhealthy (10). Chang and Herzog (11) noted the "withdrawal, shyness, and seclusion" of these persons that often occur following discharge from the hospital setting. Thus negative reactions from others may interfere with the process of self-acceptance and can re-
result in a decrease in activity level resulting from social withdrawal.

Engelhardt (12) stressed the unique "interest in human activity that most clearly identifies occupational therapy" (p 667). Through its use of activities, occupational therapy provides a setting wherein the patient may develop self-acceptance and the skills necessary for the accomplishment of activities out in the community. "A therapist is trained to estimate what the patient's capacities are, what the environment requires, and where further growth or learning is possible" (10, p 114).

Andreasen and Norris (13) discussed the effect of burn trauma on a person's activity level. Specifically, they found that the vocational and recreational components of self-identity are impaired by burn injuries.

Sexual dysfunction as a concomitant of physical disability has become a topic of concern for health professionals in the past decade. Literature addressing sexuality as it relates to physical disability appeared most concerned with the spinal cord injured patient population. Studies with this group revealed positive correlations between sexual competence and overall activity level (14), a relationship of interest to occupational therapists.

Concerning burned adults, few articles addressed sexual competence as it related to the actual burn injury. Sexual competence was typically only alluded to through discussions of the social and psychological implications of burn trauma. That is, the concept of sexual competence was usually addressed implicitly through consideration of the effect of the injury on activity level and social competence. No research could be found supporting a relationship between activity level and sexual competence within a sample of burned adults.

We concluded from the literature that a clarification of the relationship between activity level and sexual competence could potentially broaden the significance of the activity-oriented approach of occupational therapy intervention in burn rehabilitation. If activity level were found to be related to sexual competence, then occupational therapy's success in increasing patients' activity involvement could positively affect their overall social and sexual competence, thereby expanding the scope of occupational therapy's contribution to health care.

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Statement of Purpose
The purposes of the pilot study were threefold. First, it attempted to explore the self-reported activity level and degree of sexual competence in adults who had sustained disfiguring burn injuries. Second, it assessed the relationship between activity level and sexual competence in burn-disfigured adults. Third, it compared the activity level of adults who had sustained disfiguring burn injuries to the activity level of adults with nondisfiguring physical disabilities.

Methods
Subjects. The subjects were five male and five female long-term inpatients and outpatients who had sustained disfiguring burn injuries and who met the following criteria: age between 18 and 65 years; ability to speak and read English with a sixth-grade vocabulary level; no history of having received any psychotropic medications prior to the injury; and no history of institutionalization in a psychiatric facility prior to the injury. The average age of the subjects was 30.2 years. Average body surface area (BSA) of burn was 37.5 percent, and average number of years since injury was 2.2.

Instrumentation. The following questionnaires were administered together after patient consent:
- Modified Needs Assessment Questionnaire. The Needs Assessment Questionnaire (NAQ) was developed by Burnett and Yerxa (15) to ascertain the independent living needs of physically disabled residents of West Los Angeles. To assess the self-reported activity level of the subjects, a subtest of the NAQ that measured confidence with activities of daily community living was used. This subtest made up the Modified Needs Assessment Questionnaire (MNAQ). The MNAQ operationally defined "activity level" as the subject's reported confidence in activity participation involving either ADL or school/vocational, home chore, cognitive problem solving, social-recreational, or community mobility events. Test-retest reliability of the subscales ranged from .18 to 1.0.
Burn Sexuality Questionnaire. The Burn Sexuality Questionnaire (BSQ) was developed by the principal investigator. It explored body image and social comfort, and was used to determine the degree to which subjects reported being able to interact comfortably with others in terms of sex drive and sexual acts. Internal consistency reliability for the social comfort scale was $r = 1.0$, and $r = .35$ for body image.

**Results**

Overall, the data collected revealed a moderately strong positive correlation between activity level and sexual competence ($r = .50$). In exploring the relationship between characteristics of subgroups of the sample and the outcome variables, some predictions were supported, and others were not.

As predicted, burned females scored lower in confidence in school/vocational activities than did burned males. However, burned males scored lower on the body image factor than did burned females. As expected, individuals with $>30$ percent BSA of burn scored lower in confidence in school/vocational, cognitive problem solving, social-recreational, and community mobility activities than did individuals with $<30$ percent BSA of burn. Contrary to expectations, individuals with hand burns scored higher in confidence in ADL activities than did individuals without hand burns. Surprisingly, individuals with face burns scored higher in confidence in ADL and school/vocational, social-recreational, and community mobility activities than did burned individuals without face involvement. Unexpectedly, burn-disfigured adults did not score lower in overall activity level than did nondisfigured, physically disabled adults. Hoping to explain the findings, the differences between activity level of burn-disfigured adults and nondisfigured, nondisabled adults were explored using data from Burnett and Yerxa’s (15) sample of nondisfigured, nondisabled adults. Burn-disfigured adults scored lower in confidence in school/vocational, cognitive problem solving, and community mobility activities, but higher in confidence in social-recreational activities than did nondisfigured, nondisabled adults (see discussion section of this article).

**Methodological Limitations.** This study’s small sample size was a limitation. Although data collection remained open for 11 months in the hopes of obtaining at least 25 subjects, only 10 subjects met the criteria. Data collection was closed when it became impractical to keep it open any longer. The data are therefore not meant to be definitive, but may indicate possible trends that warrant further study. In addition, the small sample size may have reduced the power of the statistical tools used.

Because the topic of sexual competence is, for most people, a personal and private matter, the data generated by this study represent only those persons who were willing to provide information concerning their sexual experiences following the burn injury. Data were thus representative of only those who were comfortable enough with this topic to share some personal information with an investigator. The sexual competence of volunteering persons might have been significantly greater than the sexual competence of people who did not volunteer to disclose such personal information. Therefore, care should be exerted in generalizing the data beyond this sample.

A third limitation of this study relates to its dealing with a long-term patient sample. The data collected represented only those persons who remained in the same geographical area after they were burned. These data may therefore be biased by unpredictable differences between burned persons who have moved from the area and those who have not moved.

Fourth, the collected data might also be limited due to the length of time since injury for the persons sampled. If time helps people retain higher levels of activity involvement and sexual competence, then the ability to generalize this study’s data to all burned persons may be reduced.

A fifth limitation is that no comparison data could be found on the sexual competence of a nondisabled sample. This limited the certainty with which scores could be assumed to reflect the effect of the disfiguring burn injury.

Finally, low reliability coefficients on parts of the MNAQ and the BSQ might limit the confidence with which the data can be interpreted and generalized. One explanation for these may be the small sample size or the small number of items in each subscale.

**Discussion**

Findings indicated a positive relationship between activity level and sexual competence. These data suggest that occupational therapy's tradition of intervening in activity level could indirectly affect social and sexual competence. However, replication with larger samples and appropriate statistical tools are required before such a conclusion might be drawn.
Some unexpected findings raise questions that are not easily answered. If individuals with face burns do, in fact, have more confidence in ADL and school/vocational, cognitive problem solving, social-recreational, and community mobility activities than do burned individuals without face involvement, then why have we not seen many facially scarred burned persons in public places?

The principal investigator’s personal clinical impression of burned persons’ withdrawal from activity is termed “social death” by Bernstein (16). Some results of this pilot study were in contrast to statements by Bernstein (16), Woods and Andreasen and Norris (13), who described the revulsion elicited by disfigurement and the ways in which such a social response reduced the activity participation of disfigured people. The phenomenon of “social death” may be one answer to the question raised earlier, but it contradicts the findings in this study regarding confidence in activity level.

Another explanation for the findings is that burn-disfigured persons may, in fact, experience surprisingly good social adjustment. Andreasen et al. (18) described unexpected “adjustment successes” in their study of factors influencing burned patients’ adjustment during hospitalization. However, caution should be used in assuming that inpatient adjustment necessarily reflects subsequent outpatient social adjustment.

A final explanation is that denial, defined as the inability or unwillingness to acknowledge reality, is responsible for these findings. Constable et al. (19) and Cahners and Bernstein (20) are among the authors who reported that denial was commonly manifested in the rehabilitation and adjustment of burned persons. The results of the comparison of activity participation of burn-disfigured adults and nondisfigured, nondisabled adults (normals) shed some light on this. Results showed significantly greater confidence in social-recreational activities for burn-disfigured adults than for normal persons. These results further supported the explanation of denial as a factor influencing the results of this pilot study.

The finding that activity level and sexual competence were positively correlated may have reached statistical significance with a larger sample size. The possible relationship between these two variables should be investigated further.

**Practical Implications**

Patients are often perceived as asexual (21, 22). Disfigured patients are probably more often perceived as asexual and even “untouchable.” The topic of sexuality is not routinely addressed in most rehabilitation programs for burned persons. This may reflect and certainly reinforces health care team members’ perceptions of patients as asexual beings. In addition, lack of acknowledgment that sexual problems may arise might suggest to patients that sexuality is no longer an appropriate topic of concern for them. Discounting sexuality as an acceptable topic for discussion can thus have serious repercussions regarding patients’ overall adjustment. One implication of this study is that, at least for some patients, sexuality is an acceptable topic of concern to be addressed by health care team members.

The justification for occupational therapy addressing the topic of sexuality with a population of burned patients is fourfold. First, the occupational therapist is often one of the few people touching patients’ grafts or wounds, which may be purulent or bloody. The occupational therapist also handles scarred body parts and in this way may help patients feel that they are still touchable despite their disfigurement.

Second, occupational therapy programs with burned persons usually entail pain. Implementing painful occupational therapy procedures often results in a special and intimate relationship between the therapist and the patient. This may be due to patients’ vulnerability to and eventual trust in the occupational therapist as an imposer of pain.

Third, occupational therapy programs in burn rehabilitation are usually long-term, with ongoing reconstructive surgery necessitating intermittent hospitalization and therapy for many years postinjury. Because of this, burned persons may come to view the hospital as their “home away from home,” and the staff as their family. Additionally, occupational
therapy burn programs are usually intense in the number of hours spent with patients. It is not uncommon to schedule burned patients for two or three hours of occupational therapy per day. The combination of intense, long-term therapy and its associated pain serves to enhance the intimate nature of occupational therapy for burned persons.

Fourth, if activity level and sexual competence are positively correlated as suggested by the findings, then occupational therapy's involvement with activity level also may affect the patient's sexual competence. This possibility, along with the hands-on aspects of occupational therapy, lends support to further clinical and research concern with the topic of sexuality.

Another implication relates to denial as a factor manifested in burned persons' overall adjustment. Severe burns resulting in extensive disfigurement may actually require denial as a method of coping with the injury (23). Health care team members should be aware of denial and the ways in which they may unintentionally foster it. For example, a graft that is "beautiful" medically (that is, good surgical results) will probably not seem "beautiful" to the patient. By overlooking this distinction, health care team members may actually foster denial.

Another clinical implication is that health professionals should be aware of the relationship of denial to the "good patient" role. For example, staff may view social participation as signs of a cooperative patient and good adjustment. However, social interaction in an effort to please the staff may necessitate and thus reinforce denial. Team members should be alerted to the effects of their personal values and expectations on patient denial.

A more radical implication regarding denial might be: In a severely disfigured population, is denial "good" adjustment? If so, should occupational therapy foster denial? These questions have been raised in literature addressing adjustment to hemodialysis (24-26); they warrant further attention.

A final clinical implication concerns community and social programming along with public education regarding disfigurement. The results suggest that certain burned persons might be at high risk of having a negative body image or decreased activity level (for example, burned females with 30 percent BSA). Community and social treatment programming may be indicated for these people. In addition, public education regarding disfigurement could facilitate disfigured persons' adjustment to a society that is more accepting of their participation and sexuality.

**Suggestions for Future Research**

The results of this pilot study pointed out a need for further research on the relationship between activity level and sexual competence with a larger sample size of burn-disfigured adults. Longitudinal studies are indicated to assess changes in adjustment over time. A need exists for research measuring denial as a factor of burn rehabilitation. Correlational studies relating denial and confidence in activity level and denial and sexual competence are indicated. Such information would help clarify the role of denial in the adjustment process of burn-disfigured adults. A paradox exists in that if denial is determined to be high, then self-reports of activity level and sexual competence might be inaccurate. Methods other than self-report should be considered.

This study also revealed a need for research on the effect of health professionals' values on patient denial. Staff members may value and encourage socialization regardless of the extent of disfigurement, necessitating increased patient denial. Assuming that denial negatively affects adaptation, programs aimed at helping staff identify the effects of their personal value systems on patient behavior could be implemented. Changes in staff awareness on this matter could then be compared to changes in the degree of denial demonstrated by patients.

The need for research on the sexual competence of nondisfigured physically-disabled adults was also established. Comparison of such data to data on the sexual competence of burn-disfigured adults could provide information on the effect of disfigurement on sexual competence. Also, other disability groups such as amputees should be studied to determine the applicability and generalizability of this study's findings.

Finally, the results of this study suggest the need for a quasi-experimental study of the effect of increased community programming on the activity level, sexual competence, and amount of denial of burn-disfigured adults, assuming denial could be accurately measured. Patients could be randomly assigned to two occupational therapy programs. The experimental program would have a component of intense community programming, such as frequent shopping trips or community outings such as going to the movies.
The other would have the traditional occupational therapy elements, including a small amount of community activities. Differences in resulting degrees of activity level, sexual competence, and denial could then be assessed.

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