A Survey on Issues in the Lives of Women With Severe Mental Illness

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Objective: **Women with severe mental illness were surveyed to explore issues in living with mental illness, personal relationships, and professional relationships and health care. The topics were drawn from the literature on the psychology of women and from separate focus groups of therapists and mental health care consumers. The women's survey responses were compared with men's responses to an equivalent survey to determine if the issues affected women and men similarly.** ***Methods:*** **A 76-item questionnaire was completed by 107 women and 59 men from ten rehabilitation centers in Maryland.** ***Results:*** **A larger proportion of women than men cited personal relationships as their most important formative experiences, with only 32 percent of women citing severe mental illness or related issues as formative experiences. Despite acknowledging the negative impact of severe mental illness on their lives, most respondents reported normal concerns rather than illness-related ones, and most were relatively satisfied with their lives. Respondents made sense of their problems in diverse ways, although most knew their diagnosis. Women reported both more and better quality personal relationships than men. However, women were more likely than men to report a history of sexual abuse. Women reported generally good relationships with providers. About one-quarter to one-third of women reported not receiving proper care for birth control and menopause and not receiving pelvic or breast examinations.** ***Conclusions:*** **The survey results suggested that personal relationships are central in women's lives, that women with severe mental illness do not see their mental illness as the main feature of their identities, and that women's experience of living with severe mental illness is considerably different from that of men. (*Psychiatric Services* 48:1273–1282, 1997)**

Gender differences in schizophrenia and other severe mental illnesses have been little studied. In 1977 Wahl (1) found "uniform neglect of potential sex differences" in three major journals on severe mental illness. In 1992 Wahl and Hunter (2) concluded that this imbalance "leaves a knowledge gap about females with schizophrenia and, at worst, creates false expectations." The study reported here attempted to bridge this gap by exploring women's views in three broad areas: issues raised in living with a serious mental illness, interpersonal relationships, and health care and relationships with health care providers.

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Background

Although the literature on gender and severe mental illness is sparse, it dates back to Kraepelin (3), who described dementia praecox as occurring only among men. Recent literature supports the idea that women and men have different susceptibility to different forms of schizophrenia (4–6). Women have better premorbid competence, later onset, fewer negative symptoms, more affective symptoms, and less time in the hospital than men (7–10).

The female hormone estrogen has antidopaminergic properties that may protect women from more severe expression of schizophrenic and psychotic affective symptoms (4,11). Women with schizophrenia tend to show more severe symptoms before puberty, after menopause, and just before menstruation, which are times when estrogen levels are reduced (4,11,12). Gender differences have also been found in other axis I disorders (10,13). Postpartum psychoses have been studied in a wide variety of cultures and seem to be at least partly attributable to the decrease in estrogen after giving birth (14–22).

In addition to biologically based differences, socially based gender differences are likely to be important for an accurate understanding of the experiences and needs of women with severe mental illness. Furthermore, the biological and social differences interact with one another. Apfel and Handel (23) argued that because women with schizophrenia are more likely than their male counterparts to have florid, or positive,

symptoms and are also more likely to have primary responsibility for child care, parenting would be more stressful for a married mother with schizophrenia than for a married father with schizophrenia.

The feminist literature suggests that women in general have different socialization experiences than do men, which results in different characteristic strengths and weaknesses (24–26). "Relational theory," developed by Miller and her colleagues (24), suggests that relationships with others are the central source of empowering energy and psychological growth for women. If a woman's relationships are not satisfying, or if the woman feels a sense of psychological disconnection from her partner, the result is psychological turmoil and a corrosion of self-worth and identity.

More specifically, relational theory posits that when a woman experiences mutual, validating relationships, she will have more "relational zest," a greater range of competencies, a more complex sense of self, and a greater sense of self-worth (24, 25). If a woman instead feels shut off or disconnected from others, she will not only lack the benefits of empowering relationships, but she will be psychologically weakened and made vulnerable by the sense of disconnection that she feels (24).

If relational theory applies to women with severe mental illness, relationships should be more central to them than to men with severe mental illness, and the impact of relationships on the women's identity and experience should not be obscured by the impact of their illness. Empirical evidence supports the relationship orientation of women with severe mental illness. For example, women with schizophrenia tend to have better premorbid social competence and better social networks than do men (27).

The purpose of this study was to explore issues that have been identified as relevant to women with severe mental illness, to obtain preliminary normative data for this population on these topics, and to determine whether "women's issues" are also relevant for men with severe mental illness.

Methods

Issues studied

The choice of the three main areas of inquiry—living with severe mental illness, personal relationships, and professional relationships and health care—was based on their prominence in the literature, their mention in first-person accounts, and their salience to focus groups of women with severe mental illness.

Living with severe mental illness. Three topics were explored under this heading. First, we inquired how women viewed their mental health problems. In previous studies, more than one-quarter of respondents with severe mental illness did not believe they had an illness and gave alternative explanations for their symptoms (28–30). In our study, we wanted to explore whether women and men gave different explanations. Second, because severe mental illness profoundly impacts a person's life, we were interested in finding out how it affected women's sense of themselves as women and their general satisfaction with life. Third, we explored their formative experiences and their current goals.

Personal relationships. Under this heading we explored four areas: friendships and social support, abuse, romantic and sexual relationships, and parenting.

Social support is an important buffer against stress. Being able to give support to others is a source of feelings of competence and psychological growth for women, particularly when the relationship is mutual and reciprocal; women tend to rate their same-sex friendships as being more mutual than men rate theirs (31). Natural social support networks have been found to be useful in maintaining and reintegrating women with schizophrenia into the community (32). Previous studies have highlighted some of the difficulties that women with schizophrenia have with marital and dating relationships (33). In this study, we looked for social support in the form of relationships with friends, family members, and organizations. We also explored helping relationships in which the study participants themselves provided social support.

Sexual abuse is a fairly common experience in this population. Goodman and her colleagues (34,35) report rates as high as 65 percent for childhood sexual abuse and 76 percent for adult sexual abuse among currently or formerly homeless women with severe mental illness. Lipschitz and coworkers (36) found lower rates among female psychiatric outpatients—55 percent in childhood and 29 percent in adulthood. Friedman and Harrison (37) found a 60 percent lifetime prevalence among women inpatients with schizophrenia, compared with 13 percent among normal volunteers. Miller and Finnerty (38) reported a significantly higher incidence of rape and sexual abuse among women with schizophrenia-spectrum disorders than among control subjects. Regarding incest, studies of general psychiatric inpatients and outpatients typically find rates between 25 and 44 percent (39).

Sexual abuse can be particularly devastating when the perpetrator is someone in a position of authority, especially in psychiatric settings, where the therapeutic environment fosters vulnerability and requires trust (40). Although reliable epidemiological data have not been collected on the prevalence of abuse within psychiatric institutions, anecdotal evidence suggests that in the past it was not rare and that many current consumers have histories of abuse that took place within the system (41,42).

As for physical abuse, Goodman and her colleagues (35) found that 87 percent of a sample of formerly homeless inner-city residents with severe mental illness reported childhood physical abuse, and that 87 percent reported physical abuse in adulthood. These rates are higher than those reported by Lipschitz and associates (36)—36 percent in childhood and 46 percent in adulthood.

Studies of the sexual and romantic relationships of women with severe mental illness have typically focused on difficulties or pathologies rather than on normative functioning (23, 36,43–48). Jacobs and Bobeck (47) have indicated that mental health clinicians do not, as a rule, ask their

clients about their sexuality, and that clients are often reluctant to bring up the issue.

Most of the literature on parenting and severe mental illness has focused on fertility rates, parenting skills, or the effect of the mother's illness on the child (48–51). Until recently, the professional literature and the mental health care system typically viewed a patient's pregnancy as simply a problem, rather than as an occasion for a complex choice that a patient might legitimately be able to make (23,52). When experiencing or contemplating pregnancy, women may have concerns about the effects of psychiatric medications on the fetus and the milk supply (43). (Schwab and colleagues [53] and Zemencuk and colleagues [54] have provided detailed analyses of parenting issues among persons with severe mental illness.) Coherent state policies addressing the needs of mothers with severe mental illness are rare (55), although some exemplary individual programs exist (56).

Professional relationships and physical health care. The work of Handel (57) suggests that women with severe mental illness infrequently receive physical and pelvic examinations. Even when gynecological symptoms appear, the problems may not be diagnosed, because mentally ill women's complaints of abdominal pain may be dismissed as psychiatric symptoms.

In a study in Japan, women with schizophrenia had more negative perceptions of their body's attractiveness, health, and proportions than did female college students (58). These results, coupled with the finding that many psychotropic medications lead to weight gain (43), suggest that concerns about body image may also be prevalent among American women with severe mental illness.

Some writers have argued that women with severe mental illness are commonly devalued or treated like children by clinicians (22). Other writers have focused on the relationship between client and therapist and have suggested that the therapy's effectiveness depends on the extent to which the client experiences a genuine connection with the therapist (25,59). Various forms of therapy have been reported to be effective with women with severe mental illness (60–63), but Perreault and associates (64) reported a gender difference in satisfaction with outpatient therapy. We therefore asked our participants to characterize the quality of their relationship with providers and therapists.

Two focus groups consisting of women with severe mental illness helped develop the survey instrument.

Survey instrument

Three focus groups—two consisting of women with severe mental illness and one consisting of mental health clinicians—helped develop the survey instrument. The focus groups were held in the winter and spring of 1993.

The two focus groups of women with severe mental illness were created by inviting women from a psychiatric clubhouse and from a hospital-based day treatment program to participate in a discussion about women's issues. Each group contained about ten women. Topics selected for inclusion in the study were those that the focus groups deemed important, that were potentially relevant to most women with severe mental illness, and that had implications for therapeutic interventions. Focus groups also provided substantial editorial assistance to ensure that the wording of the survey would adequately reflect the respondents' experience. These methods have been described in more detail elsewhere (65; Coursey RD, Lucksted AA, Keller AB, unpublished manuscript, 1995). A pilot study was conducted to verify that the questions and the instructions were comprehensible.

The final questionnaire included 76 items, 70 of which were multiple choice questions and six of which were open-ended questions. (A copy of the questionnaire is available from the authors.) The men's version of the questionnaire was substantially the same as the women's version except that gender references were reversed and women's reproductive health items were omitted.

Ten sites in various communities in Maryland participated in the study. Two-week test-retest reliability data were gathered from one of the larger sites. Previous projects using the same population and the same questionnaire development methods have found high test-retest reliability measures of 74 percent, 74.3 percent, and 82 percent (29, 30,66). In the present study, results from 16 subjects showed that 80 percent of the items were answered in the same way the second time.

The survey was administered in the spring of 1993 by a team consisting of the first author and several trained female undergraduates. The surveys for women and men were administered simultaneously in two separate rooms. A standardized script was used for the introduction and administration of the questionnaire itself. Respondents were assured of their anonymity, the survey did not ask for their names, and respondents' signed informed consent forms were separated from the survey when they were handed in. Each respondent read and filled out his or her own survey form. One-on-one assistance in filling out the questionnaire was available for those respondents who wanted such help.

Sample

A mixture of ten rural, urban, and suburban psychiatric rehabilitation centers was selected to encompass a variety of Maryland communities. One hundred and seven women and 59 men completed the questionnaire.

At two sites, consumers who chose not to participate in the study were asked to complete a one-page questionnaire on demographic informa-

tion. The demographic and diagnostic profile of those submitting complete questionnaires did not substantially differ from nonresponders or from those who completed only part of the questionnaire.

Analyses

To reduce the number of statistical comparisons, chi square analyses were conducted only on discrepancies of 10 percent or larger between women and men. In the power calculations (67), alpha was set at .05 with a medium effect size of .30. In our group of 166 participants, a 10 percent difference in responses between women and men provided a power of .80 to detect a true difference and consistently yielded a significant effect for the two-tailed test of proportions. The criterion of a 10-percentage-point difference for statistical analysis also ensured that the differences between men and women were meaningful and nontrivial. For continuous data, t tests were used to determine group differences.

For the open-ended items, a ten-member research team on serious mental illness at the University of Maryland used qualitative data analysis and group consensus to identify major categories of responses and then to sort the data into those categories. The research team was blind to the gender of the respondents during this process.

Results

Diagnostic and demographic characteristics

In this sample of respondents from psychiatric rehabilitation centers, women were more likely than men to have a diagnosis of an affective disorder (30 percent versus 5 percent), and men were more likely than women to have a diagnosis of a schizophrenia-spectrum disorder (90 percent versus 56 percent). The overall difference between genders in the distribution of the two types of illness was significant ($\chi^2=17.2$, df=1, $p<.001$). Fourteen percent of the women and 5 percent of the men had other diagnoses; there were no significant differences between the two groups for other disorders.

Forty-nine percent of both the women and the men were white, and 46 percent of the women and 39 percent of the men were African American. No racial differences were found across diagnoses.

Women tended to be slightly older than men (mean±SD age=41±11 years versus 37±8 years; t=2.7, df=151, $p<.01$) and were slightly older at the onset of their illness (mean±SD age=27±11 years for women and 24±8 years for men; t=2.1, df=138, $p<.05$).

Women and men were also significantly different in their marital status (81 percent of the men were never married, compared with 49 percent of the women; $\chi^2=16.2$, df=1, $p<.001$). The two groups did not differ in education, living arrangements, sources of income—95 percent of both groups received Supplemental Security Income or Social Security Disability Insurance—or employment. Only 2 percent had a full-time paying job unrelated to the rehabilitation center they attended.

To a large extent, the differences between the women and the men in the sample reflect differences commonly reported in the literature (4–10,29,30). Thus the differences between the genders—for example, in distribution of diagnoses—are necessary for the sample to be representative of women and men with severe mental illness in the public system. Nevertheless, the effects of these differences may be confounded with the effects of gender.

In this report, we first present the results from the entire sample, and then we present the results of a demographically matched subsample of men and women to determine whether the results for the whole sample are primarily due to gender rather than type of disorder or other variables.

Living with severe mental illness

Views on illness. Most of the 107 women (67 percent) were aware of their chart diagnosis, but one-third did not believe that they had a mental illness. One-quarter of the 59 men did not believe they had a mental illness. These proportions are similar to those found in earlier studies (28–30).

As expected, respondents' explanations of their problems varied widely. But when asked what name best described their problems, 71 percent of the women provided a response that generally matched their chart diagnosis. Forty-four percent were in exact agreement, and 27 percent gave explanations that were either synonymous with their chart diagnoses, such as "mood swings," or that included a key symptom or behavior, such as "hearing voices." The remaining 29 percent of the women did not agree at all with their chart diagnosis. Some of their explanations reflected a popular mental health model, such as "stress" or "bad nerves." Others used alternative explanations, such as "spiritual fight" or "life's troubles and woes." Men's answers did not differ substantially from those of the women.

When asked what caused their problems, women were more likely than men to cite "bad things that happened to me in the past" (45 percent versus 23 percent; $\chi^2=7.9$, df=1, $p<.01$) or "the result of the way I was raised" (24 percent versus 6 percent; $\chi^2=8.4$, df=1, $p<.005$). Only about one-third of the respondents attributed their problems to a chemical imbalance in the brain.

Impact of illness on life. When asked to assess the impact that the illness has had on their lives, respondents varied greatly in their assessment. As for the global impact of illness, most women reported being moderately affected and fewer reported that their lives were unaffected or completely ruined. About 40 percent of both women and men said that their illness had some adverse affect on their feelings of femininity or masculinity. About half of both women and men (47 percent and 51 percent, respectively) stated that their illness had forced them to give up or change some important life goals, such as having a job, having a baby, or going to college. No striking gender differences were apparent in these responses.

To gain a more balanced view of their everyday concerns, we asked respondents to state in their own words the issues that frequently occupied their minds. Three categories

emerged. First, 84 percent of the women and 93 percent of the men gave responses categorized as "normal," such as "will I succeed in writing poetry." Second, only 16 percent of the women and 15 percent of the men mentioned illness-related concerns, such as "will I ever get better." Third, normal concerns related to life within the mental health system, such as "how to get transportation to the grocery store," were mentioned by 25 percent of the women and 5 percent of the men, a significant difference ($\chi^2=6.8$, df=1, $p<.01$).

Overall, respondents varied on a life-satisfaction item in a bell-curve-like fashion, with most being moderately satisfied. Similar results have been reported in other studies (68).

Formative life experiences. We asked respondents to list up to four experiences that shaped who they are today or that they consider the most important things that ever happened to them. Five categories emerged: relationships; work, accomplishments, and striving; severe mental illness; religion; and other. Women were significantly more likely than men to cite relationships (73 percent versus 40 percent; $\chi^2=13.5$, df=1, $p<.001$), and men were more likely than women to give responses in the category of work, accomplishments, and striving (56 percent versus 38 percent; $\chi^2=3.8$, df=1, $p=.05$).

Only about one-third of the women and the men (32 percent and 37 percent, respectively) mentioned issues related to mental health, such as being incarcerated in the hospital, as a formative experience, and only a few mentioned their severe mental illness or any psychological problems at all. Religious issues such as "getting to know God" seemed about equally important to women and men (31 percent and 28 percent, respectively).

Current goals. Twenty-four life goals were identified from the focus groups and the literature. Respondents checked all applicable goals and circled the most important ones. Surprisingly, goals involving relationships were rated the top two by men, and getting a job was one of the top two items for women. Women's and men's overall rankings of goals were very similar (Spearman's r=.83).

Table 1

Rates and perpetrators of physical and sexual abuse among women and men survey respondents with severe mental illness, in percentages

Rate and perpetrator	Physical abuse[1]		Sexual abuse[2]	
	Women (N=90)	Men (N=49)	Women (N=86)	Men (N=43)
Rate of abuse[3]	71	67	57	33
Perpetrator				
Doctor	10	8	8	14
Staff	4	10	6	7
Another client or patient	13	16	6	2
Date	11	2	13	5
Spouse[4]	27	0	8	0
Parent or relative[5]	30	27	19	2
Friend	11	18	14	5
Stranger	16	27	24	14

[1] Responses to the question Have you ever been hit, beaten, kicked, shoved, slapped, etc.?
[2] Responses to the question Has anyone ever touched you in a way that made you feel uncomfortable, or raped you?
[3] Significant difference between women and men in rate of sexual abuse ($\chi^2=6.8$, df=1, $p<.05$)
[4] Significant difference between women and men in perpetrator of physical abuse ($\chi^2=15.3$, df=1, $p<.005$)
[5] Significant difference between women and men in perpetrator of sexual abuse ($\chi^2=6.6$, df=1, $p<.05$)

Personal relationships and social support

Friends and social support. Women were much more likely than men to say they had a best friend (70 percent versus 44 percent; $\chi^2=10.8$, df=2, $p=.01$), a mutual, egalitarian relationship with someone (72 percent versus 58 percent; $\chi^2=12.1$, df=2, $p<.01$), or a pet that is like a member of the family (among pet owners, 78 percent of women versus 36 percent of men; $\chi^2=9.6$, df=1, $p<.01$). Most respondents—55 percent of the women and 64 percent of the men—said that they had at least one family member who was supportive. Sixty-one percent of the women and 72 percent of the men said that they felt like a fully accepted member of their family.

Organizations. Almost half of both women and men (49 percent and 41 percent, respectively) said that they attended church. Women were less likely than men to belong to a self-help group (17 percent versus 33 percent; $\chi^2=5.2$, df=1, $p<.05$). More women than men were without any form of involvement in organizations or clubs (29 percent versus 14 percent; $\chi^2=5.2$, df=1, $p<.05$).

Helping others. Women were more likely than men to say that helping others was very important to them (70 percent versus 48 percent; $\chi^2=7$, df=1, $p<.01$). However, women and men were equally likely to say that helping others made them feel good (77 percent and 78 percent, respectively).

Abuse. Women reported widespread abuse of many kinds. Most women and men (76 percent and 72 percent, respectively) reported having experienced at least one type of abuse. Perpetrators were most often men, and they included relatives, friends, and psychiatric service providers as well as strangers. Victims varied greatly in age. Women with affective disorders or schizophrenia-spectrum disorders were about equally likely to report having experienced abuse.

As Table 1 shows, physical abuse was widely reported by women. Almost three-quarters of the women respondents reported at least one experience. The most common abusers were parents, with incidents involving parents reported by about a third of women respondents.

More than half of the women (57 percent) reported at least one incident of sexual abuse (see Table 1), compared with 33 percent of the men, a significant difference. Nineteen percent of the women, compared

Table 2

Responses of women and men with severe mental illness to survey questions on romantic and sexual relationships, in percentages

Question and N of respondents[1]	Women	Men
Do you have a long-term romantic partner? (99 women, 57 men)		
Yes[2]	48	19
No, not right now	53	81
If you don't have a partner now, why?[3] (47 women, 41 men)		
Prefer to focus on my own needs right now	55	39
Don't know why	29	34
Prefer not to have one now	27	15
Difficult to get to know people	17	29
Prejudice keeps me from getting a partner who is up to my standards	10	0
People are uncomfortable approaching me	10	2
If you have a partner, is the relationship satisfying to you? (40 women, 10 men)		
Yes, very satisfying	50	60
Yes, somewhat satisfying	38	30
No, not at all satisfying	12	10
Are you satisfied with your current sex life? (86 women, 53 men)		
It is exactly the way I want it to be	36	30
It is okay, but it could be better	28	25
I am very dissatisfied with it	17	28
Not sure	19	17
Is it hard to talk to staff or therapists about your sex life?[3] (93 women, 55 men)		
Too embarrassing or uncomfortable	38	40
Yes, because they never ask about it	13	22
Yes, I don't want to bring it up	18	13
No, it is not hard to talk about it	46	33
Not sure	8	11
Is having a good sex life a goal that you might want to discuss in therapy? (91 women, 54 men)		
Yes	24	33
No	59	43
Not sure	17	24
If you are bisexual or lesbian (gay), can you be openly gay or "out of the closet"? (79 women, 51 men)		
This question does not apply to me	81	70
There's a place I can be openly gay	1	2
At least one person knows and accepts	3	10
No, can't be openly gay, though I'm gay	15	18
If you wanted to have a homosexual relationship, or if you had sex with another woman (man), would you feel comfortable discussing it with your therapist? (92 women, 47 men)		
Yes, probably	11	23
No, probably not	23	13
Not sure	4	11
I would never have romance or sex with another woman (man)	62	53

[1] Some questions have been paraphrased here for brevity.

[2] Significant difference between men and women ($\chi^2=12.2$, df=1, $p<.005$)

[3] Respondents could select more than one answer.

with only 2 percent of the men, reported being sexually abused by a parent or relative, usually the father. The difference in rates of sexual abuse was signficant. About one-fourth of the women said that they had been sexually abused by strangers, all but two of whom were men. However, women were more likely than men to usually be able to refuse unwanted sex (73 percent versus 59 percent), and men were more likely than women to "never be able to say no" (26 percent versus 5 percent; $\chi^2=7.2$, df=2, $p<.03$).

Romantic and sexual relationships. As Table 2 shows, women were signficantly more likely than men to report having a romantic partner (48 percent versus 19 percent). Among women who did not have a partner, the most common reason for not having one, selected by 55 percent, was "I prefer to focus on my own needs right now."

About half (55 percent) of the sexually active women surveyed reported that they used birth control. When asked about the effects of their medication on their sex life, about one-third of both male and female respondents said that it impaired their sex life in some way.

For gay people, being unable to be openly gay with anyone could be a significant source of alienation and isolation that would tend to erode the effects of the other forms of support (69). Among the 19 percent of the female respondents who identified themselves as gay or bisexual, 79 percent said they felt unable to confide in anyone about issues related to homosexuality. The proportion of women in our sample who identified themselves as gay or bisexual is comparable to the proportion of women with severe mental illness in Miller and Finnerty's sample (38) who reported having had a same-sex partner (17 percent, compared with 2 percent of control subjects).

Almost one-third (30 percent) of male respondents identified themselves as gay or bisexual; 60 percent of these respondents said they were unable to be openly gay. However, because the survey questions on homosexuality had low response rates, these percentages should not be used as an accurate estimate of the prevalence of homosexuality among mentally ill men.

Parenting. Women were far more likely than men to have had at least one child (62 percent versus 17 percent; $\chi^2=18.8$, df=1, $p<.001$). Contrary to the view that adoption is the norm in this population, most parents (82 percent of the mothers and 66 percent of the fathers) reported raising or helping to raise at least one of their children. Twenty-seven percent of the mothers reported that at least one of their children was living with them. Of the 33 children who lived with their parents with severe mental illness, 70 percent were school-aged or younger. Most parents (81 percent of mothers and 66 percent of fathers) reported being in contact with at least one of their children.

Among respondents who answered a question about the effect of severe mental illness on parenting, 29 percent of the women and 11 percent of

the men said that the illness had made it harder for them to be a good parent ($\chi^2=5.1$, df=1, $p<.05$).

Professional relationships and health care

Physical health. Among women respondents, about a third reported not receiving regular breast exams (29 percent), pelvic exams (25 percent), birth control care (35 percent), or menopause care (35 percent). These findings are similar to those reported for the general population. Most women (80 percent) reported being satisfied with the information available to them about sexually transmitted diseases.

Because many psychotropic medications are contraindicated for pregnant women, pregnancy poses special problems for women with severe mental illness (23). More than half of the women respondents (56 percent) said that if they became pregnant, they would worry that they might have to stop taking their medications and, consequently, have a relapse. Similarly, more than half (59 percent) would worry that the medications would harm the child, either before birth or during breast feeding.

Respondents were also asked about several appearance-related side effects of their psychiatric medications. The most commonly selected item was weight gain; women reported it as a side effect more often than men (60 percent versus 44 percent; $\chi^2=3.8$, df=1, $p=.05$). Although women were indeed more likely than men to see themselves as overweight (75 percent versus 42 percent; $\chi^2=16.4$, df=2, $p<.001$) and were more likely to be making an effort to lose weight (70 percent versus 33 percent; $\chi^2=21.2$, f=3, $p<.001$), they were not significantly more likely than men to be generally uncomfortable with their appearance (18 percent versus 14 percent).

The focus groups suggested that it might be common for women with severe mental illness to feel that their physicians view them as mentally unreliable, do not take their complaints seriously, and do not routinely ask for relevant medical history. This hypothesis was not supported by the survey results. Only 5 percent of the women said that their physicians "hardly ever" took them seriously. Similarly, only 7 percent felt that they were "hardly ever" asked for relevant medical history.

Relationships with mental health care providers. The majority of women indicated that the staff members at their rehabilitation center made them feel "respected" or "like an equal" (74 percent) rather than like "a child" or "just another case" (25 percent). More than half of the women (61 percent) reported that staff members asked them what they wanted in their treatment plans, while a quarter (26 percent) reported not being asked. These results appear to disconfirm the assertion made by some of the focus groups that women with severe mental illness typically feel disconnected from or infantilized by service providers.

The findings were consistent with the idea that severe mental illness itself is not the center of these women's identities.

Most women also reported having good relationships with their psychotherapists. Seventy-eight percent reported that their therapist made them feel "respected" or "like an equal," and 22 percent said their therapist made them feel like "a child" or "just another case."

As expected, women did seem to be more attuned than men to certain subtle aspects of their relationships with their therapists. Questions about these aspects were intended to be operationalizations of relational theory in the form of behavioral signs that the client and therapist were experiencing "connection" (24). Women were more likely to have an opinion about whether or not their therapist ever seemed moved by what they said, whereas men were more likely to be unsure ($\chi^2=10.3$, df=3, $p<.05$). The same pattern was found when women and men were asked whether their therapist had learned anything from them ($\chi^2=7.4$, df=2, $p<.05$) and whether their therapist tried to understand their culture or background ($\chi^2=14.9$, df=3, $p<.01$).

What researchers and the general public should know. An open-ended item asked respondents to say in their own words what they wanted researchers and the general public to know about them. Some women wanted others to be aware of their limitations or special needs (38 percent), such as their difficulty working or being homemakers; some mentioned their competencies (14 percent), such as their ability to be independent; and some mentioned the need for more community resources (8 percent). However, the need for respect from other people was the most common response, and women were significantly more likely to mention the need for respect than men (66 percent versus 36 percent; $\chi^2=6.7$, df=1, $p<.01$).

Matched subsamples

To disentangle the effects of gender differences from other factors, we repeated the original analyses with a subsample of 52 men and 52 women matched for diagnosis, age, race, education, and employment. There were no other differences on sociodemographic variables except marital status. Analysis of this matched subsample by gender produced essentially the same results as the analysis by gender in the main sample.

Of 104 analyses (mainly Pearson chi square tests) with adequate cell frequencies, 97 had the same results as in the larger unmatched sample—either significant or not at the .05 level. Of the remaining seven comparisons, six were in the same direction as the differences in the unmatched sample, but did not reach the significance level due to the smaller sample size.

Two further comparisons were made within the women's group to

test for the impact of diagnosis and marital status. The pattern of survey findings across diagnosis—schizophrenia versus affective disorders—in a subsample of 90 women produced no evidence that diagnosis affected any of the significant variables. Indeed, the only two significant findings were counter to expectations about diagnoses. Finally, we examined findings for married women versus never-married women in a subsample of 98. Significant differences occurred only on questions about children and about physical and sexual spousal abuse, but not on any of the other variables for which significant differences between men and women were found in the main analyses.

The lack of findings for these two subsamples was not due to lack of power. Indeed for an alpha of .05, the power to detect a true difference was .60 for a medium effect size of .30. Rather, these results suggest that the findings from the total sample are indeed primarily attributable to gender effects rather than to diagnosis or marital status.

Discussion and conclusions

The findings on women's experiences in living with severe mental illness were consistent with the idea that severe mental illness itself is not the center of these women's identities. Only a few respondents mentioned their illness when they were asked to list the main experiences that shaped who they are today. Similarly, when the women were asked to describe their most pressing concerns, almost all of the responses were categorized either as "normal" or as due to the logistical or lifestyle ramifications of living with severe mental illness rather than as characteristics of the illness itself.

However, most women said that their illness had some adverse impact on their lives. Our survey did not explore whether this adverse impact was caused mainly by the illness itself or by its secondary consequences, such as joblessness or homelessness. Some adverse secondary consequences, such as a limited social network, may affect women differently than they affect men.

Despite acknowledging the negative impact of their severe mental illness, respondents typically reported being relatively satisfied with their lives overall. This finding raises the question of how they have psychologically worked through the dissatisfaction or loss inherent in the handicapping effects of severe mental illness (70).

One way of coping with a problem is to try to understand it and find meaning in it. The way respondents understood the causes of their problems varied widely. About a third of the women surveyed believed that they did not have a mental illness, even though most of these women were aware of their official psychiatric diagnoses. Although the medical model is typically presented to clients as the "correct" explanation, evidence that clients' belief in other nonpsychotic explanations is necessarily maladaptive has not been found.

The findings on personal relationships and social support are consistent with relational theory, which holds that women are more oriented than men are toward participating in close relationships.

Research is needed on how people can develop a clear understanding of their illness and how they can best use that understanding to cope with the disorder. Such information could enrich the content of psychoeducational classes and other materials given to consumers and their families.

Overall, the findings on personal relationships and social support are consistent with relational theory, which holds that women are more oriented than men toward participating in close relationships. This finding may mean that the men in our sample have less developed relational skills, either as a result of their socialization as males or as a result of their illness, or both. Unfortunately, our data do not directly address this issue.

The finding that more women than men cited relational formative experiences also supports the concept of gender-specific socialization processes operating in this population even before the onset of the illness. This finding also agrees with those reported elsewhere that women with schizophrenia tend to have had better premorbid social functioning than men, which also may be at least partly attributable to a biologically based difference in the expression of schizophrenia across gender (8). Regardless of the origin of these differences, the women in this study maintained some mutual relationships despite the negative impact that severe mental illness presumably had on their ability to sustain such relationships.

Unfortunately, most women reported having experienced at least one abusive relationship; they were more likely than men to report sexual abuse, but about equally as likely as men to report physical abuse. These findings suggest that clinicians should routinely include abuse issues in their assessment of new clients (71,72). Aside from being an important clinical issue in itself, abuse may trigger the onset of severe mental illness or play a role in its course or expression of symptoms (73). Clinically, the internal quieting that results from resolving the psychological issues springing from abuse sometimes helps clients with severe mental illness cope with their illness.

It is hard to compare the rates of abuse in this sample with those in the general population, because we did not have a control group of persons without severe mental illness. The findings on sexual abuse are

consistent with those of other studies of persons with severe mental illness, which have reported rates of 51 to 76 percent for women (35,37, 74,75) and 26 percent for men (75). The two empirical studies that had normal control groups found significantly lower rates in the control group (36,37). Furthermore, anecdotal evidence from respondents' comments during data collection suggested that our current findings might reflect some underreporting. Several respondents mentioned to the investigators they did not answer questions about abuse because they did not wish to recall upsetting memories of extensive abuse. In a study by Williams (76), more than than one-third of sexual abuse survivors did not recall the episode 17 years later.

In the area of professional relationships and health care, both women and men generally reported good relationships with their physicians, psychotherapists, and rehabilitation center staff. We did not find the levels of disrespect that might be expected from the nonempirical literature (22) or from our focus groups. This difference could be due to recent improvements in the mental health system, attention to issues of respect by some advocates, or a positive response bias by the respondents.

It seems reasonable to hypothesize that women with severe mental illness would have difficulty creating and maintaining relationships of connection with therapists and staff members, given the high staff turnover in many treatment settings and the geographic instability in consumers' lives caused by the typically short hospital stays and frequent changes of residence. Despite these obstacles, the respondents seemed to be generally satisfied with their relationships with service providers. This finding is similar to reports in other studies of relationships with therapists in this population (29,66). Although the literature stresses the importance of continuity of care (65), in today's managed behavioral health systems it would be useful to develop effective methods of coping with the discontinuities.

The sample for this study was representative of clients of psychosocial rehabilitation centers in Maryland. Due to the great variability between states in the quantity and quality of services and service providers, some of the findings may not be representative of the experiences of women with severe mental illness in other states. Persons with severe mental illness who are financially independent, who are homeless, or who are chronic hospital patients may also have different points of view. ♦

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