

# Coping With the Dual Demands of Severe Mental Illness and Parenting: The Parents' Perspective

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## **Abstract**

The experience of parenthood by individuals with severe mental illness has not been well studied. Research on mentally ill parents has focused on their pathology and the potential risk for their children without considering the parents' perspective. This qualitative study used interviews to explore how these parents coped with the dual demands of parenthood and their illness. Participants included individuals whose children are now young adults as well as those with younger children. Themes that emerged were problems with diagnosis and treatment, stigma, chaotic interpersonal relationships, the strain of single parenthood, custody issues, relationship with children, social support, and pride in being a parent. Follow-up interviews focused on the themes of relationship with children, strain of single parenthood, and sources of support. Relationship with children contained three specific topics: discipline, boundary issues, and role reversal. Implications for practice are discussed along with recommendations for future research involving other family members.

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THE EXPERIENCE OF PARENTHOOD by individuals with severe mental illness has not been well understood. Because parenting is a highly valued social role, there is extensive literature on parenting and the development of parenting skills in general. However, the special circumstances of parents who have severe mental disorders such as schizophrenia, major depression, and bipolar disorder have rarely been addressed. Most of the research on mentally ill parents has focused on their pathology and the potential harm to their children with little consideration of the parents' perspective (Goodman & Brumley, 1990; Gopfert, Webster, & Seeman, 1996; Jacobsen & Miller, 1999). Although some parents with a severe mental illness may present a potential risk to children in their care, only those families that experience a serious crisis receive attention because of their involvement with the child welfare system (Blanch, Nicholson, & Purcell, 1994). The experiences of parents who struggle with severe mental disorders but who manage

to successfully raise their children has not been a focus of research. While the community mental health movement has enabled many mentally ill individuals to become integrated into their communities, the parenting role of many of these clients has typically been overlooked by the mental health system (Nicholson & Blanch, 1994; Oyserman, Mowbray, & Zemencuk, 1994). We are just beginning to appreciate the importance of parenthood for these clients, along with the challenges they face in confronting the complex demands of parenting and their illness (Fox, 1999; Mowbray, Oyserman, & Ross, 1995; Sands, 1995).

Because this subject is not well understood from the parents' perspective, a qualitative, exploratory design was used in this study, building on prior qualitative research on this topic. For example, Sands (1995) interviewed mothers with chronic mental illness living in an urban area in the eastern part of the United States. The majority of the participants in this study were African American with low incomes. Partic-

ipants in the current study are from small cities and rural areas in the Midwest, are all Anglo American, and while some have low incomes, others hold blue-collar or white-collar jobs. Despite these differences in the two samples, the current study and the Sands study are similar in that participants were interviewed about their experiences as parents with a severe mental illness, and how their mental illness and parenting affect each other.

Other recent qualitative studies have consisted of focus groups of mentally ill mothers who have young children. One study in the northeastern United States (Nicholson, Sweeney, & Geller, 1998) examined these mothers' experiences with their families, exploring issues regarding the quality of social support they received from family members. They found that family members did often provide important social support to these women, but that these relationships were complex and not entirely positive. Another study in Australia (Bassett, Lampe, & Lloyd, 1999) also used focus groups to explore the parenting experiences of mentally ill mothers with children under age 5. The major themes that emerged were loss of custody, trauma of hospitalization, social isolation, stigma, care of the child if the mother becomes ill, access to community services, need for consistent staff, and their relationship with their children. Many of the themes found in these previous studies also emerged during the interviews in the current study. While the current study complements previous research, one key difference is that the sample is not limited to parents of young children. By including parents whose children are now adolescents or young adults, the interviews were able to incorporate a broader historical perspective of these parents' experiences that has not been previously explored.

Although results of qualitative inquiry may not generalize to a larger group, they are inherently valid representations of mentally ill parents' views of their experiences (Rapp, Kisthardt, Gowdy, & Hanson, 1994). Furthermore, it provides a better understanding of how these parents socially construct their experiences by allowing them to discuss these experiences in an open-ended, narrative fashion. This study augments previous qualitative studies by exploring similar questions but with a different demographic group and in a different geographic and cultural setting. It adds to our knowledge of this phenomenon by incorporating a broader perspective of parenting experiences over time. It also serves to validate the importance and reliability of any recurrent themes that have emerged in previous studies. This may in turn lead to further studies that can incorporate these themes into their design.

## Method

A qualitative research design was used in this study in order to obtain a deeper understanding of the topic from the participants' point of view. The goal is to identify recur-

ring themes and concerns as a particular group—parents with serious and persistent mental illness (SPMI)—experiences them. The purpose in using this research method is to understand, rather than predict (Royse, 1989). A qualitative design is relevant in areas where there are gaps in understanding a social phenomenon, and is particularly useful for understanding the phenomenon from mental health consumers' perspective (Rapp, Kisthardt, Gowdy, & Hanson, 1994). The current study used techniques derived from grounded theory for data gathering and analysis. However, because the goal was to describe rather than develop an underlying theory, it was not completely a grounded theory design. Rather, it used the grounded theory techniques of constant comparison and theoretical sampling in conjunction with narrative history. Data gathering and analysis used the constant comparative method and theoretical sampling techniques developed by Glaser and Strauss (1967). Constant comparison is a systematic method for gathering, recording, and analyzing qualitative data in which narrative data are analyzed and coded concurrently with the gathering of additional data (Strauss & Corbin, 1990). Theoretical sampling refers to sampling concepts relevant to a developing theory rather than sampling from a frame to approximate population parameters. Theoretical sampling was the used in this study as the basis for sampling decisions for both the initial round of interviews as well as the subsequent round of follow-up interviews.

Criteria for inclusion in the sample required a history of treatment and at least one hospitalization for a serious and persistent mental illness, defined as either a psychotic disorder (e.g. schizophrenia) or severe mood disorder (e.g. major depression or bipolar). Persons with other mental disorders, such as alcohol or substance abuse and personality disorders, were included only if they had a primary SPMI disorder. Because other studies have focused on parents of preschool or school age children, it was decided to broaden the sampling criteria to include parents whose children are now adolescents or young adults in order to obtain a longer historical perspective of their parenting experiences. It was also decided to include both parents who have lost custody of their children as well as those with custody. The decision to include parents whose children are now older allowed for the inclusion of parents who had either temporarily lost or voluntarily relinquished custody of one or more children for a period of time, but who later regained custody of at least one child. We also included parents who had permanently lost custody due to their mental illness. The theoretical reason for these decisions was to allow for a broader perspective not reported in other recent qualitative studies on this topic. Specifically, several previous studies where custody concerns have been mentioned focused on parents living in poverty and involved with the child welfare system. We wanted to explore whether other SPMI parents also share these concerns, and to identify those factors that parents

believed enabled them to either maintain or regain custody of their children. Participants were recruited from several consumer and family support groups and from community mental health centers throughout central Illinois.

During the first series of interviews participants were asked to provide some background information and to briefly discuss their treatment history. The interviewer then posed a series of questions and follow-up probes asking participants to discuss how their mental illness had affected them as parents. These queries were then followed by questions about how their experiences as parents, in turn, affected their mental illness. Otherwise, these interviews were relatively free of predetermined structure and allowed the parents to formulate their ideas as part of the interactive interview process. During the initial interviews it became apparent that the participants viewed their experiences with their illness, their personal relationships, and their experiences as parents as inextricably interwoven. As a result, the structure of the interviews evolved into a narrative history form, with probes and follow-up questions serving to guide the discussion.

In adopting the constant comparative method, the research team went through several stages of coding to analyze the narrative data. The first stage, open coding, involved carefully reading transcripts of the recorded data, line by line, with open assignment of categories ascribed to the data. During this stage, both the researcher and the research assistant coded the interviews individually. Thus, a process of evolving and negotiating meanings and categories occurred. These discussions led to the next stage of axial coding. In this stage data were reorganized in new ways by making connections between the categories and constructing broader themes. Concurrent with the coding of the initial interviews, the themes that emerged guided questions in subsequent interviews.

To further explore these themes the research team conducted a second round of follow-up interviews. Data collection decisions for the follow-up interviews were guided by theoretical sampling concepts as described by Strauss and Corbin (1990). The goal of theoretical sampling is to sample concepts, incidents, or behaviors that are significant in light of the developing ideas and themes that can sharpen the researchers' conceptualization. With this in mind, we selected five participants whose initial interviews suggested greater exploration of the developing themes identified during axial coding and who represented a cross-section of the initial sample. Four of these five participants agreed to participate in follow-up interviews at this stage.

The second round interview questions were more structured and focused on theoretical concerns but continued to be open-ended and again asked for the participants' perceptions of their experiences in a narrative fashion. First, the parents were asked to confirm background information and to elaborate on any diagnostic or treatment information

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that may have been unclear in the initial interview. They were then presented with a synthesis of the initial interview and asked to verify or comment on the categories and themes that had been identified. Themes that were explored fell into three categories: relationship with children, sources of support, and the strain of single parenthood. The category of relationship with children contained three specific themes: discipline, boundary issues, and role reversal. Sources of support included both informal supports, such as family or friends, and formal supports, such as social service agencies. The strain of single parenthood included both economic and emotional difficulties that resulted from divorce, as well as ongoing concerns and struggles regarding custody.

While the follow-up interviews were being conducted, axial coding continued to be done with the original interviews. Following the second round of interviews and the ongoing data analysis, saturation of categories occurred. The final stage of selective coding was performed with connections made between the various themes and categories.

### **Participants**

Thirteen parents who have an SPMI disorder agreed to participate in the study. Nine of these 13 participants are active clients of community mental health centers across central Illinois, so the presence of an SPMI disorder was confirmed for each of them by their respective agency. The other four participants were recruited through mental health consumer groups in the area. They provided detailed information regarding their diagnosis and treatment for SPMI. This information was discussed in-depth during both the recruitment and interview process. Three of these four participants

had a confirmed diagnosis that met the research criteria for an SPMI disorder, while one participant's diagnostic information was unclear. She no longer has active symptoms nor receives active treatment, but she did have a documented hospital stay and several years of treatment for psychotic symptoms in the past. This mother is currently an active member of mental health consumer groups and represents a group that is often overlooked in research, i.e., individuals who have achieved a high degree of recovery following treatment for a psychotic disorder. Despite the fact that her clinical history and life experiences were different from the other participants in the study, the decision was made to include her insights and experiences in order to compare and contrast them with those of the other participants.

Our sample of 13 parents consisted of 12 women and 1 man. Three are currently married while the remaining 10 are separated, widowed or divorced. Ten of the participants have at least a high school education, with 4 reporting anywhere from 1 year of college to graduate studies. Seven participants reported having lost custody of their children at some point and another one reported having joint custody, but her children's primary residence was with their father following her divorce. Four of those who lost custody later regained custody of at least one child, 2 permanently lost custody as a result of divorce (one of these was the only father in our sample), and 1 gave her children up for adoption. Five parents reported at least one child who has a psychiatric or behavioral disability of some type.

## Themes

### **Problems With Diagnosis and Treatment**

Because the interviews began with an exploration of each individual's experiences with her or his illness, it was not unexpected that over half of them (8) described difficulties related to their treatment. What was notable is that many of them struggled for years with either an uncertain diagnosis or a misdiagnosis that further complicated their attempts to manage their illness. As a result, their ability to fulfill their role as a mother or father was jeopardized. The theme of unrecognized or inadequately treated mental illness resounded through many of the interviews. One participant stated,

*It was never recognized that I had a mental illness. Everybody felt like this was a behavior.... Snap out of it.... You should be over it by now. I didn't really get the right diagnosis until after my kids were practically raised.*

This particular mother went through a series of therapists and counselors, and was diagnosed at one time with a personality disorder before finally receiving the correct diagnosis of bipolar disorder. Unfortunately for this parent, her children were in late adolescence before the correct diagnosis was made. Similarly, many of the parents interviewed

reported suffering for years with an incorrect diagnosis or experienced inadequate treatment, which impaired their ability to be an effective parent during acute episodes of their illness. Another parent reported:

*I've been diagnosed everything.... One said I was a paranoid schizophrenic and the other one said no I wasn't.... You know, when you get a different doctor, they see what they think they see, and do the best they can, you know ... and some of them want to medicate you to death, and, you know, not deal with your problems and not talk to you. I had one doctor ... he gave me too much shock and I was in a coma for 3 weeks.*

Many participants recognized that their symptoms during acute episodes compromised their parenting ability. One parent reported, "Before I started medicine ... I was on the couch for many months ... barely taking care of them." For many parents, this created a crisis situation for their families when their condition became severe enough to require hospitalization. The manner in which these parents coped with these crises is discussed further in the sections on social support and custody issues. It was also clear that for the majority of these parents their acute symptoms abated with proper diagnosis and treatment. However, they continued to struggle with the handicap of being labeled mentally ill.

### **Stigma and Discrimination**

The harmful effects of stigma for persons with a severe and persistent mental illness have been well documented. Therefore, it is not surprising that stigma and discrimination emerged as a theme in the interviews. Particularly noteworthy is that this theme was as important to the one parent who has achieved a high level of recovery as with the other study participants. Stigma affects mentally ill parents in several ways. First, it has a chilling effect on their willingness to seek help and engage in treatment. This aspect of stigma is directly related to the earlier theme of problems with misdiagnosis and treatment. As one parent put it,

*I had problems, but my husband wouldn't listen to me. I self-diagnosed myself as schizophrenic.... Yeah, I just diagnosed myself ... and I didn't want to go to a psychiatrist because I thought he would lock me up and I wanted to raise my kids.*

A second aspect of stigma the parents in our study discussed focused on concerns about losing custody of their children. They discussed reluctance to seek treatment as being based in part on fear of losing custody if diagnosed with a psychiatric disorder. In fact, those parents who went through a divorce reported having their diagnosis used against them. This was sometimes done through formal court custody decisions, but was just as likely to involve

acquiescence on the part of the mentally ill parent when faced with a threat by the former spouse. For those parents who experienced either a temporary or permanent loss of custody via the child welfare system, most felt that their diagnosis was also used against them by child welfare workers. Thus, their adverse experiences associated with custody concerns and fear of losing their children reinforced their perceptions of discrimination due to the stigma of their mental illness.

The last aspect of stigma discussed was based on the parents' concern for their children. One parent described harassment and verbal abuse that her daughter experienced at school and in her neighborhood. As a result of this harassment, this mother and her adolescent daughter (who has also been diagnosed with a mood disorder) became reclusive, further compounding the social withdrawal that accompanies their illness. Other parents discussed general concerns about the subtle types of discrimination their children might (and sometimes did) experience at school or in their neighborhoods as a result of their parent's illness. The one mother who is in a high level of recovery expressed these same concerns about her own children, despite the fact that she is an outspoken advocate for mental health consumers and has been free of symptoms for many years.

### **Chaotic Interpersonal Relationships**

All the study participants had been married at some point, and all but two subsequently went through a divorce. One exception is the parent who experienced a psychotic episode at an early age and did not marry or have children until several years later when she had already achieved a high level of recovery. In contrast to the other parents, whose divorce exacerbated their illness, she discussed the importance of her relationship with her husband as a protective factor in helping to cope with her illness and to prevent relapse. The other exception was a woman whose husband had died in recent years. She viewed his death and her subsequent grief as being the stressors that triggered her mood disorder. All the other participants saw their mental illness affecting their relationships in one of two ways. They either viewed their illness as contributing to the difficulties they were experiencing in their relationships, or they believed their illness was exacerbated by these relationship problems. One mother described this interaction between her illness and the problems in her relationship in the following manner:

*I got the medicine, but I only took it for a short while because that's when the divorce hit.... He thought I was crazy.... When your mind is sick, it is like you are under water just waiting for it to pass and finally you come up for air, you are waiting for it to pass, how long am I going to be under this time? That's what it's like.... He couldn't understand or anything. He was tired of it, he said, "I can't take you mentally anymore." ... I was just*

*crushed.... Eventually I couldn't decipher reality from nonreality and I finally put myself in the hospital.*

In addition to difficulties maintaining a relationship with their significant other, many of the participants also reported strained relationships with their parents or siblings. On the one hand, these family members were a key source of support during times of crisis, especially in regard to childcare. However, their relationship to the participant was at times strained due to these demands, and they were often described as being very critical and emotionally non-supportive. This theme is explored further under the heading of social support.

### **Strain of Single Parenthood**

A few other qualitative studies of parents with SPMI have identified single parenthood as a significant theme (Sands, 1995; Bassett, Lampe, & Lloyd, 1999). This was also a recurrent theme throughout the interviews in this study. Whether participants viewed their mental illness as being exacerbated by the break up of their marriages or whether they also saw their illness as contributing to their failed relationships, the end result was the same. At a time when they found themselves most emotionally vulnerable and under stress due to their loss of a significant other, they typically experienced a major emotional or psychiatric crisis. The one exception was the participant whose acute phase of her illness preceded her marriage and children by several years and who did not divorce. She believed that the success of her marriage enhanced her recovery and felt that her husband acted as a protective factor during times of stress, reporting

*So, part of it is I feel that I am more aware of how stressors affect people's lives ... having children and parenting has not been a particular stressor.... I have a wonderful support network, my husband is fabulous in being a support.... I would say that far and away is the most important thing. I couldn't imagine doing it without that openness and support.*

In addition to the support of her spouse, which was missing in all the other interviews, she cited other forms of social support as key factors, "I have a great friendship network.... Having a work setting that accommodates day care, parental concerns, makes a big difference."

During their emotional and psychiatric crises, these parents found themselves caring for one or more children while dealing with the financial and emotional problems that accompany single parenthood. One mother expressed the financial hardship by saying, "I know one thing that is very hard on a single parent. When he left, the money left. My security went and their security went." Another parent described her struggle with these dual demands during an acute episode of her mood disorder following her divorce:

*I tried to get work and the kids were giving me problems because they were demanding more attention now that they knew I was in trouble. I didn't know what to do... I was starving but it didn't matter to him, he just wanted me to take care of them like I always had.*

### **Custody Issues**

Eleven of the 13 participants expressed concerns about losing their children through either divorce or child welfare. The two exceptions were (a) the atypical case whose marriage and childrearing came several years after she recovered from the acute phase of her illness, and (b) another participant whose symptoms became acute following the death of her husband 4 years prior to the interview. Seven of these 11 parents had actually lost custody on at least a temporary basis, but only 3 had lost custody on a permanent basis. Although custody concerns were an ongoing stressor for most of the participants in the study, they were particularly acute during times of a psychiatric crisis. It was during these times that these parents were most in need of support from family or friends for care of their children. Because of their temporary inability to adequately care for their children, they were vulnerable to losing their children. A theme that echoed throughout the interviews was that parents with SPMI recognize and appreciate having someone take care of their children during these times of crisis or hospitalization. However, they are very concerned that these incidents may be used against them in custody decisions as a result of either divorce or involvement with the child welfare system.

### **Relationship With Children**

Three themes emerged under this category: discipline, boundary issues, and role reversal. These three themes were interwoven in the parents' narratives, and each impacted on the other two. Discipline is an important issue because it is seen as a key parental responsibility that requires judgment and restraint that may be compromised by mental illness. Many of the parents interviewed admitted to having some problems in this area and were more likely to see themselves as too lax or permissive than too harsh. Several parents expressed this by saying, "I look back and see that I maybe should have set a few more rules," or "I was never good about rules ... my biggest problem was consistency and discipline." Some expressed this as a consequence of their own perceptions of inadequacy and the guilt they felt about being a mentally ill parent. One mother expressed a sense of guilt due to the impact her mental illness and chaotic relationships had on her children, "I was not good at saying no, because I felt sorry for them [because they had been through so much] ... I tried to make their life easier."

A common experience the interviewed father had with many of the mothers was loss of custody. He expressed his lax approach to discipline by saying, "I would let them do things that she wouldn't let them do... I was able to be

more lenient with them. I didn't have to discipline them or anything." Many of the parents described a tendency to be more lenient as a result of only seeing the children during visitations and wanting to enjoy the brief periods of time they spent with their children. One mother who lost custody as a result of her divorce said,

*Because our time initially was so little together, why spend it yelling and screaming and making them do chores when they're gone in 2 days... When they came to my house we were going to have fun.*

A few parents reported problems with excessive discipline that occurred within the context of an acute episode of their illness. One parent reported,

*I only spanked them when they got into something that could hurt them... Sometimes when I was sick I would go overboard with the spankings... So as far as discipline goes, I used to discipline them when I was sick, and it was wrong. So now I don't punish when I'm sick... I shy away because I've done it in the wrong way before.*

A few other parents also recalled instances when their psychotic or manic symptoms made them dangerous to their children. In these instances both professional intervention and support from a family member or friend who could temporarily take care of the children were needed. However, the more frequent theme found in the interviews was a lax or permissive approach to discipline that was accompanied by a special sense of closeness between the parent and their children.

Most of the parents characterized their relationship with their children as a special bond that helped them get through tough times. They typically described this bond as something that developed over time as a result of going through the hardships the family faced. Following the death of her husband, one mother characterized her relationship with her daughter as follows:

*Well, it's made us closer. She used to be a daddy's girl. She wouldn't have anything to do with me. And since he died we have become closer. I support her in every which way there is that I can possibly think of, and she supports me.*

Although they readily admitted that their children often had more expectations placed on them and faced special burdens due to the participant's mental illness, the parents also believed these hardships eventually led to a closer, mutually interdependent relationship with their children. However, during the data coding process it became apparent that these descriptions of close bonds with their children also suggested themes of role reversal and boundary issues.

Role reversal was apparent in two respects. First, during times when the parent was experiencing an exacerbation of their symptoms, older children often had to act as a parent in assuming responsibility for taking care of younger children or helping with household chores. One mother described her relationship with her daughter during an acute phase of the mother's illness by saying,

*You know, she was doing the parenting! And she took care of [her brother], in terms of taking him around in the wagon.... She became the little parent sometimes, and because she had that little bit of responsibility or something, it made it even worse for me to parent her!*

In another example of this, one mother described the following scenario that occurred during her major depressive episodes:

*My kids have had to come home and, you know, had to help with the housework and "well, mom's not well so we have to fix supper tonight," or you know, things around the house ... and it was tough on me, having to ask my kids.... I mean, all of them helped a great deal.*

The second aspect of role reversal was when the child and parent would switch caregiver roles during these times when the parent was incapacitated. This ranged household chores such as cooking for the parent, to cueing the parent to take their medicine or alerting the parent or other adults that the parent's symptoms were becoming worse. One mother described her dependence on her daughter in the following way,

*That was difficult for my daughter.... During the week I would sit [my son] beside me and I would watch cartoons or whatever, a lot times my head was really out of it.... My daughter had to help, she still thinks that was the pits. [At other times when her symptoms became worse] they would tell me. I would tell them to tell me; I would say, "Tell me if I am not making sense, because I need to know, it is important."*

Although their relationships with their children were strained at times because of these extra demands, all of the participants reported a sense of a special closeness with their children. In some respects, these parents' views of these relationships appeared to be healthy and mutually beneficial. However, it also appeared that some of the descriptions of these relationships were excessively idyllic and suggested possible problems with establishing appropriate boundaries between parent and child. As shown in some of the quotes above, several parents reported difficulties in exerting their parental authority due to the role reversal that occurred as a result of acute episodes of their illness. Other parents saw

their relationship with their children as filling the void created by divorce or chaotic relationships. One mother referred to her sons by saying, "Who needs a husband! My kids did it." A more clear example of problems in establishing clear boundaries due to symptoms of their illness is exemplified in the following comments by one mother, "But me and [one of her sons] were like soul mates. Anything that happened to him, I could feel it.... He is like an angel." Therefore, it was difficult to discern in a few of the interviews whether the special bond that many of the parents described was a sign of healthy affection and mutual support, or whether it was an indication of impaired cognition and perceptions due to the participant's mental illness. It is very likely that many of these parents do have a healthy and reciprocal relationship with their children. However, workers should be alert to this issue and include an assessment of whether the individual parent is able to clearly establish boundaries between their own emotional well-being and that of their children.

### **Social Support**

Those parents who had a strong social support network, whether it was family, friends, or church were able to cope with crises better than those who were more socially isolated. The most important issue they identified is having someone who can step in and help with the children during times of a psychiatric crisis or hospitalization. Parents who did not have this support, either because they did not seek it out or because it was not readily available, were more likely to have lost custody their children at least temporarily. In addition, neighbors and friends were also mentioned as people who would step in and supervise the children or assist with household chores that the parent viewed as being essential to the children's well being. Other types of support the participants in the study identified as important were having emotional support from friends or family and receiving financial support from their ex-spouse or their relatives. Finally, the few individuals who are currently in a stable relationship reported that the emotional support they receive from their spouse plays a significant role in their ability to cope with both their illness and their responsibilities as a parent.

The persons most frequently mentioned as providing support in times of crisis were female family members, usually a mother or sister. However, several individuals also mentioned their ex-spouse or the ex-spouse's relatives, such as their mother-in-law, as providing support in times of crisis. Informal supports such as family and friends were mentioned much more frequently than formal, professional sources of support such as case managers, social workers, or agencies. However, clients actively involved with psychosocial rehabilitation services through their community mental health center were more likely to mention professional forms of support.

Although most of our participants readily acknowledged their sources of support, they also described their relationships with those in their support network in complex terms. This was particularly true when their primary source of support was family or an ex-spouse. Similar to the findings by Nicholson, Sweeney, & Geller (1998), most participants described mixed relationships with relatives. On the one hand, parents or siblings provided a good deal of financial and child-rearing support for the children, but they were not often described as a good source of emotional support for the mentally ill parent. Several participants characterized their relationships with their family in the following manner:

*They did step in and help me out, but sometimes their good intentions were the worse thing for me. Sometimes they tended to take over and they had the children a lot ... also they got on me a lot ... [and told me to] snap out of it.*

*My sister, I got support from her, and she took care of the kids when I stayed in the hospital for 3 months.... My sister, my families are mixed about me being sick.*

*I believe it takes a village to raise a child. Even though I didn't appreciate my family at times, and my ex-husband, I felt that everybody was important for my kids.... Even though I knew what they were saying, I didn't counteract it with "No, your mom isn't crazy."... I didn't need that bickering.... They weren't supportive of me.*

### **Pride in Being a Parent**

All the parents who spent any period of time raising their children described the self-esteem they derived from the parent role. They expressed this through such statements as:

*I think the joy of being a parent, for me, adds to mental health.*

*I think I am more complete because I am a parent.*

*It has helped me. I am proud to be a mother; I am happy to be a mother; I love being a mother.*

*I enjoy working, but when it comes right down to it, it's my kids that are most important.*

Every participant in the study, including the one parent who voluntarily gave her child up for adoption, expressed genuine concern for her or his children. This was evident in a number of ways. Most of the parents who lost custody described some effort to maintain contact despite separation. Those who permanently lost custody or gave their children up for adoption reported reconnecting after the

children became adults. Typically, the children initiated these contacts, indicating the importance of these relationships to them as well. Many of these parents are now providing some type of support for their adult children. Typically this support has come in the form of serving in the grandparent role or by providing emotional support, and was reported by parents who had lost custody as well as those who had maintained custody.

### **Discussion**

One of the implications of this study is the need for early intervention and treatment for parents with SPMI. Consistent with the narratives of several of the participants in this study, bipolar disorders are often misdiagnosed initially because some of the more severe symptoms are often treated as psychosis, while the less severe symptoms are either overlooked or seen as a personality disorder or substance abuse. A recent survey (Mondimore, 1999) found that 73% of the individuals with bipolar disorder in the study received at least one incorrect diagnosis prior to being correctly diagnosed. Although diagnostic procedures have improved in recent years, social workers and other human service workers need to be particularly sensitive to the need for comprehensive assessments when working with a parent who has a severe mental disorder. Assessments that rely too heavily on initial symptoms may result in an inaccurate diagnosis that can have far-reaching consequences for both the parent and their children. Both mental health professionals and caseworkers in child welfare need to include assessments of the parents' functional abilities, their social support system, and their ability to handle the complex interpersonal demands of parenting (Ackerson, in press). A comprehensive approach that includes both a functional assessment of the mentally ill parent along with an assessment of the family environment will facilitate proper diagnosis and treatment for the parent as well as determine what types of supports and services are needed for the family as a whole. Therefore, multidisciplinary assessments that link mental health agencies with agencies that provide children and family services are essential (Blanch, Nicholson, & Purcell, 1994).

Stigma and fear of losing custody often prevents these parents from seeking treatment. Therefore, developing strategies to successfully engage mentally ill parents in treatment must address these concerns. Because many of these parents are not aware they have a severe but treatable mental or emotional disorder, they do not seek treatment until a crisis occurs. At these times they may be hospitalized, and their children may come to the attention of the child welfare system. In other instances their ability to care for their children is impaired by their illness, which results in their involvement with the child welfare system. Unfortunately, because child welfare workers are often poorly trained regarding severe mental disorders and because their first



concern is for the children's safety, issues regarding whether to remove the children or terminate parental rights are often their primary concern. Unfortunately for many mentally ill parents, this may be their first contact with human service workers and reinforces their perception of stigma and discrimination, serving to undermine their willingness to engage in mental health treatment. Even parents who are not involved with the child welfare system may find their diagnosis or treatment history used against them by an ex-spouse, as was reported by parents in this study.

Therefore, we need to adopt a proactive approach to working with parents who have a severe mental disorder. First, workers need to join with family and consumer groups to battle the problem of stigma through advocacy. Next, because many parents with mood and anxiety disorders go to a primary care physician rather than seeking mental health treatment (Badger, Ackerson, Buttell, & Rand, 1997), we need to create better linkages between health care professionals, child welfare workers, and mental health professionals. Finally, it has been observed that community mental health agencies have traditionally ignored the parenting roles of their most severely ill clients (Nicholson & Blanch, 1994; Zemencuk, Rogosch, & Mowbray, 1995). Addressing parenting issues in psychosocial rehabilitation programs and other services in the community mental health system provides a more proactive approach than waiting until parents with SPMI are in a crisis and come to the attention of the child welfare system.

Boundary issues and discipline are key areas that need to be addressed by those working with mentally ill parents in improving parenting skills. Mental health professionals are rightly concerned about these individuals' abilities to distinguish proper boundaries between themselves and their children, and to establish age-appropriate rules and expectations for their children. Behavioral research has shown that impaired problem-solving abilities along with unrealistic expectations of children's behavior are better indicators of child maltreatment than a mental illness diagnosis (Azar, Lauretti, & Loding, 1998; Azar, Robinson, Hekimian, & Twentyman, 1984). Therefore, assessment of discipline practices and perceptions of age-appropriate behaviors is crucial for work with parents who may have impairment in their cognitive abilities or regulation of their emotions due to a severe mental illness. However, workers

also need to consider the significance that their children hold for these parents. The perceptions of closeness and bonding with their children that the parents in this study reported are indicators of strong affection, which are a potential strength that can be used to engage parents with SPMI in services and treatment.

Role reversal may be a concern if too many demands are being placed on a child at too early an age, but it may also be a source of considerable support for both the parent and child. The stories of mutual reliance described in many of the narratives implied a beneficial effect for the children in terms of fostering their sense of responsibility and maturity as well as creating a stronger parent-child bond. From the parents' perspective, the ability of an older child to help with household chores or to supervise younger children provided a safe home environment during times when the parent experienced greater impairment

due to their illness. However, this issue needs to be studied further from the children's perspective. A comprehensive assessment of the home environment and social support system should include questions and observations of both the adults and children's roles within the home. It is also important to consider that these roles may be fluid, and that greater demand is likely to be placed on the child during times of crisis or an exacerbation of the parent's symptoms than at other times. The enhancement of both formal and informal supports for the parent during these times should also reduce the need for relying on their children.

## Conclusion and Recommendations

Parents who have a severe mental illness have the same desires to care for their children and to perform well in the parent role as other parents. They take pride in being a parent and are fearful of having their children taken away from them. It is noteworthy that only a few of the parents we interviewed described the demands of parenting as having a detrimental effect on their illness. Rather, the majority of them felt the emotional benefits of parenthood outweighed the stress they experienced. However, they must cope with a disorder that at times challenges their ability to effectively carry out the parenting role. For many of the parents in our study, the fear of stigma and fear of losing custody of their children had a chilling effect on their willingness to seek

**It was also clear that for the majority of these parents their acute symptoms abated with proper diagnosis and treatment. However, they continued to struggle with the handicap of being labeled mentally ill.**

treatment. Relationship problems with significant others and the strain of single parenthood often exacerbated their mental disorder and undermined their ability to cope. Once they sought treatment, difficulty in obtaining an accurate diagnosis or effective treatment compromised the ability of some of these individuals to function effectively as parents. They were aware of a need for help in areas such as discipline and relationships with their children. They were able to describe their use of social support both during times of crisis and as ongoing support in managing their homes and caring for their children. However, some of them described almost idyllic relationships with their children that suggested possible problems in establishing realistic boundaries between themselves and their children. This is an area that individuals who work with these parents should carefully assess and address in their interventions.

Because this study focused on the parents' perspectives, further research involving the children, spouses or ex-spouses, and other members of the parents' social support network is needed. The themes of role reversal and social support that were discussed by the parents in this study involve complex social interactions that place demands on other members of the family. Previous research has examined caregiver burden experienced by family members of persons with severe mental disorders (Mueser, Webb, Pfeiffer, Gladis, & Levinson, 1996; Veltro, Magliano, Lobracc, & Maj, 1994). However, these studies have not looked at families where the mentally ill individual is also a parent. Future interviews that explore the experiences of other family members who are affected by the parents' illness would help to provide a more complete understanding of how parents who have a severe mental disorder cope with both their illness and the demands of parenting.

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