FAMILIES LIVING WITH SEVERE MENTAL ILLNESS: A LITERATURE REVIEW

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Schizophrenia is a severe mental illness, which is stressful not only for patients, but also for family members. Numerous studies have demonstrated that family caregivers of persons with a severe mental illness suffer from significant stresses, experience moderately high levels of burden, and often receive inadequate assistance from mental health professionals. Effective family functioning in families with schizophrenia may be influenced by a variety of psychosocial factors. The purpose of this article was to present a review of the social science literature related to families living with schizophrenia that has been published during the last three decades. There is general agreement in the literature that a multitude of variables affect families with a severe mental illness, such as schizophrenia. Therefore, this literature review examined the most frequently investigated variables (coping, psychological distress and caregiver burden, social support, caregiver resiliency and depression, and client behavioral problems) as they are related to families and schizophrenia.

Research on families living with a severe mental illness has been documented through various systematic studies, through the impressions of clinicians who have worked with these families, and through the reports of families themselves. Individuals with a severe mental illness have typically been mentally ill for many years and are unable to fulfill roles in society normally expected of individuals of their age and intellectual ability; thus, they are most likely to receive family caregiving. Severe
mental illness is stressful, not only for patients, but also for family members. Because individuals with a severe mental illness frequently live at home with family members rather than in institutions, it is a significant family concern. Numerous studies have demonstrated that family caregivers of persons with a severe mental illness suffer from significant stresses, experience moderately high levels of burden, and often receive inadequate assistance from mental health professionals. For families who are already confronted with a range of day-to-day problems that affect all aspects of their lives, a family member with a severe mental illness may have a significant impact on the entire family system.

LITERATURE REVIEW METHODS


All articles related to families and severe mental illness during the specified time frame were reviewed. The articles were assessed to determine the common variables that affect families living with a severe mental illness. A number of variables were consistently identified in the more than 400 articles reviewed. Numerous books also were included
in the literature review based on their significant contribution to the literature. In this paper, I will focus on the following topics: coping, caregiver burden/psychological distress, caregiver resiliency, caregiver depression, social support, client behavioral problems, and family functioning. Due to the extensive amount of social science research reviewed over three decades, the earlier research is only briefly described, while the recent research receives more detailed elaboration.

**COPING**

McCubbin and Figley (1983) described two categories of stressors that apply to the process of coping with mental illness. These are (a) normative stressors, involving transitions throughout the life cycle as family relationships change and family members grow and develop, and (b) catastrophic stressors, striking families suddenly and often overwhelming their ability to cope. Severe mental illness was identified as an example of a catastrophic stressor for the family.

There is a considerable literature base concerned with family stress and coping with severe mental illness. Hatfield (1979) investigated coping strategies among families with schizophrenia. Family members identified various types of coping resources including lectures, books, friends, relatives, individual therapy, group therapy, clergy, and parents of people with schizophrenia. Hatfield (1981) also conducted an exploratory study of family caregivers of relatives with mental illness over a 30-month period. She found that older and somewhat better educated caregivers were more effective in coping, and that their ill relatives tended to be older, to have been ill longer, and to be less functional. More difficulty in coping was reported when the relative was functioning at a higher level and was living at home or under family supervision in the community. Potasznik and Nelson (1984), who examined mediators of stress in families coping with mental illness, reported that low levels of family burden were associated with small social networks, satisfaction with support received, satisfaction with support from their self-help group, and spousal involvement.

The Center for Psychiatric Rehabilitation at Boston University has produced much research concerned with coping strategies of families with severe mental illness. Zipple and Spaniol (1987) described family adaptation and recovery with mental illness. These researchers identified four categories of coping responses among families: problem oriented, emotional, cognitive, and physical. There were a number of specific coping strategies within each of these categories such as getting and using practical advice, developing supports and resources, becoming an
advocate, joining a support group, enhancing spirituality, sharing problems and feelings with others, exercising, meditating, acquiring information, and making lifestyle changes. Noh and Turner (1987), in their investigations, found that a sense of personal control was important in enabling individuals to cope with mental illness in a family member. Terkelsen (1987) analyzed five factors that influenced the personal meaning of mental illness for family members: the extent of the family’s involvement in the daily life of the ill family member; the models of causation, symptoms, and outcomes that were assumed by family members; the natural history of the illness; the personality and life history of individual family members; and the social network. He discovered that the appraisal process among families who have a member with mental illness was complex and dynamic, and the meaning of mental illness for family members was likely to change over the course of a lifetime.

Lefley (1987) studied coping strategies among mental health professionals who had family members with severe mental illness. Eight coping strategies were ranked according to how helpful they were. The coping strategies include: education in symptoms, medication, and knowledge of the mental illness; specific suggestions dealing with patient behaviors; involvement with self-help groups; alternative living arrangements; individual or family therapy; relief from financial stress; substitute caregiving so the family can have some time away; and more understanding from relatives and neighbors. The findings showed that education, support groups, and alternate living arrangements were rated as more helpful coping strategies than individual or family therapy. Fadden, Bebbington, and Kuipers (1987) studied coping strategies used by spouses of persons with a severe mental illness. Their findings showed that the coping strategies most frequently used by spouses of persons with a severe mental illness were wishing the situation would go away or hoping for the development of a cure someday.

Several studies have focused on adaptive qualities, coping skills, and strengths of families. Birchwood and Cochrane (1990), who examined coping strategies used by relatives of individuals with schizophrenia, found a number of significant relationships among relatives’ specific coping strategies and behaviors of the patients. Parent coping strategies were related to their level of expressed emotion exhibited, which in turn affected their relatives’ behavior. Norbeck, Chafetz, Wilson, and Weiss (1991) found that family caregivers of individuals with severe mental illness believed that help in locating resources and the availability of backup care facilitated or improved their ability to cope. Obtaining specific information about the mental illness and methods for managing the family member’s behavior helped them cope as well.
Coping, caregiver burden, self-esteem, depression, and social support were assessed among 24 Black and 185 White parents with severely mentally ill offspring (Pickett, Vraniak, Cook, & Cohler, 1993). They discovered that Black families exhibited higher coping mastery ability and self-esteem and lower levels of depression. Overall, Black families bore the burden of caring for a mentally ill child better than White families. Solomon and Draine (1995) found that lower scores on general measures of coping (self-efficacy and mastery over problems) were related to greater subjective burden in families with a relative with a mental illness. Doornbos’ (1996) descriptive study of 85 families revealed that families coping with a severe mental illness have significantly more stressors than normative families, but also have clear strengths related to family coping, adaptability, and conflict management.

In a preliminary exploratory study, Wintersteen and Rasmussen (1997) found that a group of 25 fathers coping with the mental illness of an adult child exhibited emotional stress that was largely unrecognized and unacknowledged by mental health professionals. In addition, fathers tended to utilize more isolating strategies for coping with their adult child’s mental illness. Howard (1998) described the lived experience of fathers of adult children with schizophrenia using cross-sectional data gathered from 12 fathers over a 2-year period. Practice implications included immediate assessment of fathers, supportive listening, and brief therapy. Doornbos (1997), who studied the problems and coping methods of caregivers of young adults with mental illness, found that caregivers struggled with burden, grief, client symptomatology, and a negative impact on their family as a unit. The coping methods included facilitative attitudes, reliance on their faith, use of support groups, and increasing their knowledge of mental illness.

Magliano, Fadden, Economou et al. (1998) explored social and clinical factors influencing the choice of coping strategies in 236 relatives of patients with schizophrenia, living in five European countries. Problem-focused coping strategies were more frequent among young relatives and among relatives of younger patients. Relatives who had been living longer with the patient and who had poor social support more frequently adopted emotion-focused strategies. In all countries, relatives experienced higher levels of burden when they had poor coping resources and reduced social support. In a heuristic inquiry within the context of Newman’s theory of health as expanding consciousness, Yamashita (1998) reported that families used understanding and acceptance of their relative’s schizophrenia as a way of coping with the mental illness. A study of 58 families (Saunders, 1999) providing care for a family member with schizophrenia revealed that families that used more...
problem-solving strategies and coping behaviors were able to function more effectively as a family unit. The most frequently used strategies by these families were mobilizing resources, seeking spiritual support, reframing, internal patterns, external patterns, passivity, and social support. Hall (2000) examined relationships between levels of expressed emotion in 44 parents of individuals with schizophrenia and the coping strategies they used. Coping strategies were identified as: assertive action, social joining, seeking social support, cautious action, instinctive action, antisocial action, aggressive action, avoidance coping, and indirect action. The study found that coping was not generally directly related to levels of expressed emotion; however, an interaction between parent coping style and patient behavior was found to predict the level of expressed emotion.

In summary, the findings of the above research studies indicate that families cope in different ways with the stressor of severe mental illness. The consequences of family efforts to cope may be either positive or negative. The coping behaviors used may produce additional burdens on the already overtaxed family. On the other hand, some families have expressed the belief that coping with mental illness in the family has made them stronger persons who are better able to cope with life’s trials (Greenburg, Greenley, & Benedict, 1994). Family coping may involve positive actions to eliminate or reduce the number and intensity of demands, to acquire additional resources, to manage the stress of ongoing strains, and to make situations more constructive, manageable, and acceptable for the entire family.

CAREGIVER BURDEN/PSYCHOLOGICAL DISTRESS

By the mid 1970s, burden research was focusing on the relationship of the patient with her or his family. Kreisman and Joy (1974) conducted a review of the literature related to the needs and burdens of families with severe mental illness, which revealed effects of multiple hospitalizations on the family, family burden, family beliefs and attitudes toward the family member’s “deviance,” and how family attitudes determine family functioning. Thompson and Doll (1982) identified the subjective and objective burden of 125 families coping with severe mental illness after deinstitutionalization. Potasznik and Nelson (1984) found that increased satisfaction with social support networks served to decrease subjective and objective burden. Family caregivers experienced fewer burdens when their social support networks were small, perceived as supportive, and their spouse spent a significant amount of time with
the patient. Crotty and Kulys (1986) reported that the patient’s support system was an important mediator of family burden: Patients with a support system were less of a burden to their families than patients without a support system. Noh and Turner (1987) examined the relationship between family burden and the mental health of family members. They reported that burden was a major source of stress, and that mastery of the situation was found to mediate this stress. In one study during the 1980s, families’ perceptions of “profound” burdens were described through group interviews with 86 family caregivers living with severe mental illness (Francell, Conn, & Gray, 1988). As families have assumed more of the caregiver role for members with severe mental illness, high levels of psychological distress among caregivers have been documented. Research on parent caregivers (Cook, 1988) indicated that mothers showed significantly more measurable emotional distress (anxiety, depression, fear, emotional drain) than did fathers. It was reported that women’s behaviors and thoughts were influenced by their primary role as child caretakers, thereby resulting in a greater emotional investment in the caregiving roles.

In a sample of caregivers for family members with severe mental illness, Oldridge and Hughes (1992) reported that psychological distress (anxiety, depression, and insomnia) was twice as high as in the general population. Cook, Hoffschmidt, Cohler, and Pickett (1992) identified factors that influenced marital satisfaction among 131 parents of adult offspring with severe mental illness. Parents’ ability to comfort each other, parents’ gender, number of children, family income, and interpersonal sensitivity were discussed. Mothers-wives reported lower levels of marital satisfaction than did fathers-husbands. Stress of severe mental illness on the family as a whole (social withdrawal, frequent relocation, and unwanted caregiving responsibilities) was documented through personal interviews with siblings and adult children (Marsh, Appleby, Dickens, Owens, & Young, 1993). According to Rolland (1994), in a chronic disorder such as severe mental illness, there is increasing strain on family caregivers as a result of exhaustion and the continual addition of new caregiving tasks over time. The family is always “on-call” to cope with the day-to-day crises of severe mental illness. Reinhard and Horwitz (1995), who interviewed 163 parents and siblings of adults with severe mental illness, discovered that the conception of burden is a consequence of dealing with disruptive behaviors and providing instrumental and emotional assistance. Burden was more related to caregiving responsibilities than whether the caregiver lived in the same household with the ill family member. Provencher (1996) described the negative consequences on the family (e.g., physical problems, restrictions in social life,
tense relationships in the family) as reported by 70 primary caregivers of persons with schizophrenia. The most common negative consequences were the primary caregiver’s emotional problems, the disturbance in the caregiver’s performance of work, and the disruption in the lives of other adults in the household. Telephone interviews were conducted with 778 family members whose relatives had a severe mental illness (Greenberg, Greenley, & Brown, 1997). The level of psychological distress experienced by family caregivers was lower in those families whose ill family members received more mental health services and whose caregivers perceived a more collaborative relationship with health care providers.

Magliano, Fadden, Madianos et al. (1998) examined burden on the families of patients with schizophrenia and found that relatives experienced higher levels of burden when they had poor coping resources and reduced social support networks. Friedrich, Lively, and Buckwalter (1999) described the emotional impact of well siblings living with schizophrenia as “anxious and chaotic” with “lots of stress.” Negative symptoms, violent behavior, social isolation, lack of motivation, and fear regarding the potential for abuse was found to create psychological distress for these well siblings. Saunders (1999) revealed that family psychological distress was a significant predictor of family functioning. Families reported that some of the most distressing problems for them resulted from living with the positive and negative symptoms of their family member’s schizophrenia. The most commonly identified psychological problems for the caregivers were obsessive-compulsiveness, anxiety, depression, interpersonal sensitivity, and paranoid ideation. Pruchno and Patrick (1999) gathered data from 251 mothers and fathers of adults with chronic disabilities (64% had a developmental disability and 37% had schizophrenia). They reported that higher levels of burden were reported when a child with a chronic disability lived with the mother or father, when the child’s behavior had higher levels of emotional instability and lower level of functional ability, when there was a poorer parent-child relationship, and when the children had schizophrenia. The efficacy of two psychosocial interventions for families living with schizophrenia was compared by Razali, Hasanah, Khan, and Subramaniam (2000). Seventy-four patients with schizophrenia from the Culturally Modified Family Therapy (CMFT) group and 69 patients from the control group of Behavior Family Therapy (BFT) completed one year of study. The CMFT consisted of a sociocultural approach to family education, a drug intervention program, and problem-solving skills. The CMFT approach was found to significantly improve family burden as compared to the BFT approach.
In summary, the literature on families experiencing severe mental illness provides evidence that the illness creates continuing caregiver burden and psychological distress for families. Family stress can have both positive and negative effects and involves a demand for change in family functioning. Family distress reflects the family’s demand-resources imbalance and can significantly affect family functioning.

**CAREGIVER/RESILIENCY**

McCubbin and McCubbin (1989) defined resilience as those characteristics, dimensions, and properties of families that help families to be resistant to disruption in the face of change and adaptive in the face of crisis. Lefley (1990) discussed the potential strengths in families experiencing severe mental illness, such as learning to overcome negative emotions, fears, and attitudes, balancing multiple family needs, and maintaining supportive relationships and family stability. In a national survey of 131 family members, Marsh et al. (1996) discovered that the family experience of mental illness involved several types of resilience: consumer, personal, and family resilience. Personal resilience was reported by 99% of the families. Enns, Reddon, and McDonald (1999) identified resilience among 111 family members of patients admitted to a large psychiatric facility by measuring family adaptation, coping and appraisal, stressors, and resources. The utilization of family members in the care and rehabilitation of patients with mental illness was found to be beneficial to patient outcomes. Cuijpers (1999) performed a meta-analysis of 16 studies to test the hypothesis that family interventions have a positive effect on relatives of psychiatric patients. This analysis indicated that family interventions could have considerable positive effects on relatives’ burden, psychological distress, and the relationships among patient, relative, and family functioning.

In summary, researchers have begun to look for signs of resilience in families which may reduce the effects of burden. Families have strengths, resources, and expertise that they can utilize in order to deal with the effects of the crises or stressors of severe mental illness. Mental health professionals need to collaborate with families in the care and rehabilitation of family members with severe mental illness.

**CAREGIVER DEPRESSION**

Depression is a common experience among caregivers. Stress-proliferation models have been concerned with the conversion of
care-related stressors into emotional distress, specifically, depression (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). More recently, researchers have begun to examine depressive symptomatology in caregivers of families with a severe mental illness. Hobbs (1997) studied depression in 100 Black, elderly, low-income, unmarried, caregiving mothers of adults with schizophrenia. Stressors consisted of three social variables (burden of care, economic strain, undesirable life events) and one physical variable (poor physical health). Stress mediators consisted of coping and social support resources: The outcome variable was defined as depression. The results indicated support for the resource deterioration model with regard to a physical stressor and coping resources, but not for social stressors and social support resources. A study by Song, Biegel, and Milligan (1997) examined predictors of depressive symptomatology among lower social class caregivers of 103 adults with severe mental illness. The results indicated that insufficient social support was the most powerful predictor of caregiver depression, followed by caregiver burden and client behavioral problems. Steffen, Futterman, and Gallagher-Thompson (1998) studied a sample of 52 depressed female caregivers of family members with a severe mental illness. The caregivers participated in various group interventions for depression. Results revealed no significant differences among the interventions with regard to improvement in depression scores. Pruchno and Patrick (1999) examined 251 mother and father caregivers of adults with two chronic disabilities: developmental disabilities and schizophrenia. The sole significant predictor of depression for fathers was caregiver burden. Mothers who were more depressed had adult children whose behaviors had higher rates of noncompliance and violence, whose own physical health was poorer, and who had higher levels of caregiver burden. In-depth interviews with 50 caregivers of a family member with a severe mental illness were studied to identify how the caregivers managed their intense emotions over time (Karp & Tanarugsachock, 2000). Results revealed that efforts to deal with a mentally ill family member aroused strong emotions due to the fact that severe mental illness created threats to the order and coherence of daily family functioning.

In summary, the actual demands created by the task of providing care for a family member with a severe mental illness exert effects on the stressors of caregiving. As stressors increase and the conditions persist, the caregiver’s depressive symptomatology may worsen. The deterioration of the caregivers’ emotional health may impact their ability to continue their role responsibilities.
SOCIAL SUPPORT

Several studies have cited the positive impact of general social support on physical and psychological health (Cohen & Wills, 1985; Leavy, 1983; Wallston, Alagna, DeVellis, & DeVellis, 1983). During the past three decades, social support has been the focus of numerous research studies on mental illness. Pattison, Defrancisco, and Wood (1975) looked at social support by comparing interpersonal relationships of neurotic and psychotic patients with those of normal individuals. They found that psychotic patients not only had the smallest number of persons in their social networks, but also that the network rarely extended beyond their family. Social support of psychiatric patients hospitalized for the first time was studied by Perrucci and Targ (1982). The authors concluded that close, supportive social networks with knowledge of, and positive attitudes toward, severe mental illness were more likely to help the patient seek professional assistance when needed. Parks and Pilisuk (1984) analyzed social support of formerly hospitalized psychiatric patients who resided in supportive living homes and found that the patients were socially and psychologically isolated from their communities.

Early discussions of coping and adaptation emphasized the value of social support as a resource (Lazarus & Folkman, 1984; Zipple & Spaniol, 1987). Social support for families with severe mental illness has been identified as one of the most important family resources, since families often feel isolated and alienated from their usual channels of social support (Marsh, 1992). Chafetz and Barnes (1989) identified a pattern of coping in families with severe mental illness that included using other family members and close friends for support first and then seeking support from experienced others who have family members with a severe mental illness. Support groups have been shown to provide an effective means of reducing social isolation and enhancing social support by meeting behavioral, cognitive, emotional, and social needs of families providing care to a family member with severe mental illness.

Support Groups

The literature provides strong evidence of the value of support groups as a key component of social support for families providing care for a family member with severe mental illness (Adelson & Freeman, 1985; Atwood & Williams, 1978; Battaglino, 1987; Donner & Fine, 1987; Drescher, 1986; Hatfield, 1981, 1987; Rose, Finestone, & Bass, 1985; Rosenson, Kasten, & Kennedy, 1988; Spaniol, 1987). A
variety of family support programs that provide social support and enhance the social networks of families with mental illness have been described (Craig, Hussey, Kaye, Mackey, McCreath, Tremblay, & Vedus, 1987; Ferris & Marshal, 1987; Shapiro, Possidente, Plum, & Lehman, 1983). A reduction in family burden as well as improved emotional well-being has been reported among families with severe mental illness that belong to support groups (Lefley, 1996). A study by Winefield, Barlow, and Harvey (1998) of 36 caregivers of relatives with schizophrenia revealed useful information for mental health professionals planning to run support groups for family caregivers. The caregivers wanted better mental health rehabilitation services, accurate information regarding their relatives’ illness, and respect from mental health professionals.

Caregiving and Social Support

Social support has been considered as a significant factor in buffering caregiver stress in severe mental illness (Potasznik & Nelson, 1984). The benefits of self-help support groups for families of the mentally ill were reported in a controlled study on social support by Biegel and Yamatani (1986, 1987). Jed (1989) identified three aspects of caregiver social support that were correlated with reduced rehospitalization of their family members with severe mental illness. These were a larger number in the support network, a larger number of good advisers, and a smaller proportion of conflicted support. In a 1993 study, the personal benefits of an advocacy group, such as an Alliance for the Mentally Ill (AMI) group, were investigated among the families with severe mental illness (Norton, Wandersman, & Goldman, 1993). In a 1994 study, researchers found that social support was the major contributing factor for adaptive coping in families with severe mental illness (Solomon & Draine, 1994). The multifamily work of McFarlane (1994) indicated that participation in a family support group is an important coping strategy and a source of social support for caregivers of individuals with severe mental illness. A model of personal healing has been developed for and used with families and friends who are caregivers of individuals with severe mental illness (Johnson, 1994; Moorman, 1992).

A qualitative study of 15 caregivers (Rose, 1998) identified social support as a recognized and crucial need for caregivers of persons with a severe mental illness. Song, Biegel, and Milligan (1997) reported in a study of lower social class caregivers that insufficient social support was the most predictive of caregiver depression. In a longitudinal study, Clinton, Lunney, Edwards, Weir, and Barr (1998) examined the role of social support in community adaptation in 96 people with schizophrenia
and found that social support accounted for the largest unique variance in community adaptation. Patients with first-episode (defined as the first lifetime treatment contact) schizophrenia or affective psychosis described their supportive social relationships immediately prior to their first treatment contact and 18 months and 5 years later (Erickson, Beiser, & Iacono, 1998). Results indicated that 18-month adaptive functioning was lower than in the year prior to first treatment contact but at 5 years rose above that seen at baseline and 18 months. Social support from nonfamily members of the social support network predicted 5-year adaptive functioning in the schizophrenia \( n = 54 \) group, but not in the affective psychosis \( n = 55 \) group. Support from family members alone did not predict 5-year outcome in either group. These findings replicated and extended earlier findings that social support predicts outcome in first-episode schizophrenia. Magliano, Fadden, Madianos et al. (1998) discovered that families of patients with schizophrenia who reported lower levels of social support were more resigned and experienced higher levels of family burden. Family interventions that increased the family social network were recommended. More family social support was positively related to higher family functioning in families providing care for a family member with schizophrenia (Saunders, 1999). The findings revealed that over the years, the families had gradually learned how to mobilize the needed social support for successful family functioning.

In summary, the research findings indicate that social support for families with severe mental illness is important for families to function effectively on a day-to-day basis. Research findings indicate that social support appears to have both direct and indirect or buffering effects on mental health outcomes. Social support serves as a protective factor that facilitates coping and family functioning, thus reducing the deleterious effects of social and environmental stressors.

**CLIENT BEHAVIORAL PROBLEMS**

Symptoms of schizophrenia often require hospitalization and can be a source of burden to families (Lefley, 1987). Symptoms associated with a severe mental illness may include hallucinations, delusions, thought disturbances, social withdrawal, or emotional detachment (Strauss, Carpenter, & Bartko, 1974). The presence of behavioral problems poses enormous challenges for the entire family system. Family members have described the suffering and difficulties of living with a family member’s symptoms of schizophrenia, as well as the ways they have used their own experiences to assist other people (Dearth, Labenski, Mott, & Pellegrini,
During the active phase of a severe mental illness such as schizophrenia, psychotic symptoms are present and limit functioning in areas of self-care, social relations, and employment (Biegel, Sales, & Schulz, 1991). Some of the most distressing problems for families result from living with the positive and negative symptoms of a severe mental illness (Marsh, 1992). The positive symptoms include delusions, hallucinations, and bizarre or agitated behavior. These symptoms are associated with acute onset, a history of exacerbations and remissions, relatively normal social functioning during remissions, and a favorable response to antipsychotic medications. The negative symptoms include blunt affect, poverty of speech and thought content, apathy, anhedonia, and poor social functioning. These symptoms are associated with an insidious onset, chronic deterioration, and poor response to antipsychotic medications.

Hatfield, Coursey, and Slaughter (1994) identified those behaviors rated as most troublesome by family members. Deficit symptoms such as low motivation and poor eating and sleeping patterns were considered to be more disturbing than intrusive symptoms such as violence or drug and alcohol abuse. Those families who reported more serious symptoms also reported higher levels of family burden. Biegel, Milligan, Putnam, and Song (1994), who investigated predictors of burden among 103 lower socioeconomic caregivers of persons with severe mental illness, discovered that only one of the study’s 20 independent variables significantly predicted caregiver burden: the frequency of client behavioral problems. Results revealed that caregiver strain and family disruption were predicted by the greater frequency of client behavioral problems. The study found that behavioral problems directly impacted families who were caregivers of family members with a severe mental illness. Family burden was most associated with specific family member problem behaviors in another study, conducted by Mueser, Webb, Pfeiffer, Gladis, and Levinson (1996).

Song, Biegel, and Milligan (1997) reported that higher levels of client behavioral problems were associated with higher levels of caregiver depressive symptomatology among lower social class caregivers of persons with severe mental illness. Rose (1998), who interviewed 15 caregivers of relatives with a severe mental illness, described their efforts to regain a sense of control over apparently uncontrollable events associated with the symptoms of their relative’s illness. Fewer client behavioral problems were associated with higher family functioning in 58 families providing care for a member with schizophrenia (Saunders, 1999). Given the episodic nature of schizophrenia, families had periodic difficulties with
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family member behavioral problems, which in turn created more family psychological distress. These stressors continued to affect the family’s ability to adapt and function effectively.

In summary, the research findings indicate that families living with severe mental illness face numerous issues associated with their family member’s behavioral problems. The stressor of living with a family member exhibiting behavioral problems can have a significant impact on the family. The literature provides evidence that client behavioral problems are an important factor that influences a family’s ability to function.

FAMILY FUNCTIONING

A review of the social science literature reveals numerous studies of family adaptation and functioning (Antonovsky, 1987; Baranowski, Dworkin, Hooks, Nader, & Brown, 1986; Bernstein, Svingen, & Garfinkel, 1990; McCubbin & McCubbin, 1989; McCubbin & Patterson, 1983; Moos & Moos, 1984; Olson, McCubbin, Barnes, Larsen, Muxen, & Wilson, 1983; Russell, 1980; Steinhauer, 1984). Family adaptation and functioning are important concepts that help in understanding the family’s efforts to manage the situations created by severe mental illness. Measures of family functioning and family adaptation often are used to assess the outcome of family efforts to achieve balance, coherence, and harmony (McCubbin & McCubbin, 1993). Family adaptation consists of positive change and a successful balance among individual, family, and community levels of functioning.

Families living with a member with a chronic illness, such as severe mental illness, constantly adjust and adapt as the illness or the family situation changes (Danielson, Hamel-Bissell, & Winstead-Fry, 1993). Adjustment and adaptation to a chronic illness may result in an increase in family emotional and physical illness (Bloom, 1985; Johnson, 1985; McWhinney, 1989; Rowat & Knafe, 1985) and impaired family functioning (Miller, Kabacoff, Keitner, Epstein, & Bishop, 1986). Severe mental illness affects all aspects of family functioning, and all family relationships and roles are altered, sometimes permanently (Marsh, 1992). These alterations include finances, employment, social life, physical health, marital and family relationships, and daily household activities. Furthermore, changes in family identity may be experienced.

Saunders (1999) found that families providing care for a family member with schizophrenia were able to function more effectively as a family unit when they used more problem-solving skills, coping strategies, and
social support and experienced fewer instances of psychological distress and family member behavioral problems. Family psychological distress and client behavioral problems were identified as significant predictors of effective family functioning among these families.

In general, research on family adaptation and functioning with severe mental illness has shifted the focus away from the unhealthy, dysfunctional family to the healthy, functional family with a constant need for adjustment and adaptation. The pathology models of family functioning are being replaced by a more positive orientation that identifies the characteristics of healthy, strong, and successful families emphasizing family flexibility, integrity, predictability, and unity (Barnhill, 1979; Beavers & Hampson, 1990; Curran, 1983; Dunst, Trivette, & Deal, 1988; Fisher, Giblin, & Hoopes, 1982; Lewis, Beavers, Gossett, & Phillips, 1976; Marsh, 1992; McCubbin, Patterson, & Lavee, 1983; Olson et al., 1983; Stinnett & DeFrain, 1985). A chronic illness in families can offer positive aspects such as renewed family growth, closeness, and stability (Johnson, 1985; McCubbin, 1988; Mishel, 1990).

SUMMARY AND DIRECTIONS FOR NURSING RESEARCH

The extensive social science research literature on families living with schizophrenia published in the recent past reflects an increased interest in this area. Both quantitative and qualitative studies have succeeded in advancing our understanding and extending our knowledge of this population. In particular, the last two decades of caregiving research has provided much of the foundation for future research on caregivers of persons with severe mental illness, whose ranks will only continue to grow. However, the social conceptions of these constructs have changed over 30 years of research. The guiding theme throughout the more recent investigations is one of resilience with a focus on the strengths and adaptive capabilities of families.

Despite the increase in research effort and the quality of investigations reported, unanswered questions still exist. Examples include exploring cross-cultural differences involving ethnic minorities and developing multiple models of family psychoeducation sensitive to social and cultural diversity. Culturally-guided nursing interventions are essential. The application of innovative methods to explore unique strengths of minority families would provide a greater understanding of how culturally adaptive styles might be useful and effectively used in working with other ethnic groups. Little knowledge is available regarding the long-term health consequences of caregiving. Nursing interventions need to be guided by the following question: What can be done to increase health
behaviors among caregivers? A paradigm shift from stress response to health behavior may empower caregivers. Studies are needed that compare caregiving experiences across different illness scenarios: commonalities as well as differences in stressors and health consequences need to be identified. Caregiver burden and caregiver resilience studies need to be expanded upon, particularly in terms of caregiver depression and caregiver rewards. Families’ changing needs and readiness for specific kinds of support as they strive to cope with the challenges of caring for their mentally ill members need to be evaluated. Longitudinal research would further articulate the causal linkages between significant predictors and numerous variables, such as family coping, social support, patient behavioral problems, psychological distress, caregiver depression, long-term caregiver health behavior, and overall family functioning.

Currently, the majority of the research on families living with a severe mental illness comes from the broader social science literature, not from the nursing literature. The major disciplines represented in the social science literature are psychology, sociology, and medicine. There remains a critical need for nursing research in this area. After all, it is mental health nurses who work with these individuals and families on a daily basis. We, as mental health nurses, have the ideal opportunity to assist the families to function more independently in the community, to develop more effective coping behaviors, communication skills, and social support systems, more rewarding interpersonal relationships, and ultimately, more active decision-making skills. In addition, we value and utilize the input of the needs and desires of each of the family members. Therefore, it is essential that we continue to generate knowledge that may improve the quality of life for families living with a severe mental illness. Research on nursing interventions that specifically enhance daily coping, adaptation, caregiver health status, and quality of life for families living with severe mental illness is a potentially powerful arena for psychiatric nursing research contributions.

REFERENCES


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