Caregiver Burden, Family Treatment Approaches and Service Use in Families of Patients with Schizophrenia

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Abstract: Over the last several decades the construct of family burden has been used to capture family members’ experience of caring for a mentally ill relative. The definitions and operationalization of this experience into subjective and objective components neglects the complexity and the multidimensional nature of the caregiving experience. In addition to problems operationalizing the caregiving experience, family interventions have also neglected to address the range of issues and concerns that impact those caring for mentally ill relatives. These two factors may be significant contributors to the under utilization of family-based services by relatives of individuals with schizophrenia. Two examples of treatment programs that target the multidimensional nature of the caregiving experience (NAMI’s Family-to-Family and Journey of Hope), possible integration of these programs with family psychoeducation interventions and implications for service utilization are discussed.

Introduction

The last several decades have produced two important areas of inquiry involving families of persons with severe mental illness. One line of inquiry has focused on family burden and experience of caring for an ill relative (1–6). The other described family communication patterns and interactions (e.g., expressed emotion) which led to the development and testing of clinical models of family psychoeducation (7–11). Both lines of inquiry are important and have in their own way helped to address the needs of families and persons with severe mental illness. However, until relatively recently, they have not been connected to each other. Historically, studies of family psychoeducation have focused on patient outcomes, with less of an emphasis on whether family burden is reduced by interventions.

A corollary of this disconnection is that reduction of family burden may not be a likely targeted outcome of family psychoeducation or a clinical intervention. Szmukler and colleagues (6) raise the additional concern that the family burden construct makes assumptions regarding the relationship between family members’ distress and the patient’s illness; however, it fails to explain how the distress a family member may endure relates to the caregiving experience. Because of these operationalization problems, it is difficult to determine whether family interventions aimed at reducing family burden actually address family members’ experience of caring for a mentally ill relative. More recent reconceptualizations of the family experience provide a spring board for tailoring current family interventions to the needs of the family and, thus, may improve the degree to which individuals with severe mental illness and their family members access family based services. The present paper will provide a brief review of the family burden and family psychoeducation and how these two areas of research might be linked to improve services.

Family Burden

To better understand and describe the effect upon family members of having to care for a mentally ill family member, the concept of family burden was introduced. Burden was classified into two dimensions — objective and subjective burden (12). Objective burden refers to day-to-day practical problems such as constraints in leisure, social and work activities, loss of income, and disruption of family relation-
ships and household routines (4, 13, 14). Subjective burden describes the negative psychological impact on the caregiver and includes feelings of loss, depression, anxiety and embarrassment (4, 14).

Previous research suggests that certain patient factors may increase family burden. These factors include the severity of patient's symptoms, length of time in the hospital, number of hospitalizations, the length of time the patient has been ill, and the level of social functioning (1, 4, 15). Symptom type (positive or negative symptoms) has also received attention as a factor related to family burden, although studies have yielded equivocal results. There is evidence to suggest that positive symptom behaviors such as hallucinations and delusions along with a high degree of social dysfunction and frequent relapses are associated with greater family burden than negative symptoms of apathy and social withdrawal (4, 14). On the other hand, Dyck et al. (1) found that when examining the predictive value of positive and negative symptoms and coping style of the caregiver, negative symptoms were the most significant predictor of burden. In explaining this finding, Dyck and colleagues (1) suggest that because negative symptoms are not as episodic as positive symptoms and thus tend to have more temporal stability, they may place a greater demand on the caregiver's resources (i.e., increased need for assistance in day-to-day functioning).

Social support, age and education level are also related to level of burden (4, 14). Family members who are able to share their experience with others and who are able to draw upon both tangible (e.g., assistance with financial responsibilities and transportation) and non-tangible (e.g., emotional) support report greater well-being and less burden (14). Younger and less educated caregivers of patients with schizophrenia evidenced greater burden than did older and more educated caregivers (4, 14).

Research suggests that level of burden is reduced when family members have a more positive attitude toward the patient, when there is an increase in social support and fewer hospitalizations as well as improved social functioning for the patient (13-18). Two recent meta-analysis conducted by Cuijpers (13) and Pitschel-Walz et al. (19) revealed that family interventions significantly reduced the level of family burden. Specifically, family interventions decreased the psychological distress experienced by family members, improved family functioning and improved the relationship between the patient and family members.

From Family Burden to Caregiver Experiences

However, Szmukler and colleagues argue that this commonly used method to assess the experience of family members who care for mentally ill relatives is problematic. First, the term objective burden erroneously assumes that disruptions have occurred in the family member's "normal" life as a result of the illness. Szmukler et al. (6) and Joyce et al. (20, 21) contend that it is difficult a) to determine what the quality of life was like for family members before the onset of the illness and b) to connect disruptions in "normal" life to the patient's illness. For example, changes in activities and relationships may be attributed to the ill family member when in fact such occurrences may be the result of normal changes in activities and relationships over the course of the life cycle. Second, subjective burden is usually assessed by having participants rate the extent to which the objective burden causes them distress or by rating how distressed they are by the patient's illness. Such an approach excludes distress resulting from "non-objective" aspects of caregiving (i.e., grief over the loss of the person the patient could have become or once was) and provides little indication of how the distress may be related to the caregiving role.

To address these limitations, Szmukler et al. (6), Joyce et al. (20, 21) and Webb et al. (14) propose that research should shift from the concept of "family burden" to a "stress-coping" model of the caregiving experience. Following Lazarus and Folkman's (22) model of stress and previous work by Hatfield and Lefley (23), the impact of caring for a mentally ill relative is explained in terms of how the caregiver appraises the demands he or she experiences and the strategies in which they choose to cope with their appraisals (6). The key factors in this model are appraisals, stressors, mediating factors, outcomes and coping. According to Webb et al. (14), appraisals are how individuals evaluate an event in terms of a) what value or belief the event is threatening and b) whether the event can be changed or altered in some way.
manner. The caregiving experience is conceptualized as the manner in which the individual appraises the demands associated with the role. Stressors include the patient’s illness and behaviors, perceived disruption by the family members, and the degree of the patient’s impairment. Factors that influence the appraisals of families with a mentally ill members are conceptualized as mediating factors. These include: extent of the families’ involvement in the daily life of the ill family member, beliefs family members have about the cause of the illness, perceptions about the symptom course and the outcome, life history and personality of the family members, and the quality of social support available (18, 24).

The strategies individuals use to handle stress are defined as coping styles and are described in terms of problem-focused and emotion-focused. Problem-focused coping is believed to be more adaptive for situations that are likely to change over the course of time, whereas emotion-focused coping is more useful in situations that are persistent, chronic and unchangeable (14). In a recent review of the coping literature, Saunders (18) found that within these two categories specific coping strategies employed by family members include finding and utilizing practical advice, locating resources, participating in a support group, becoming an advocate, increasing level of spirituality, sharing with others their concerns and feelings, adopting changes in life style, and exercising. Outcomes are defined as the physical and/or psychological results of the interaction between coping and appraisals (e.g., a parent appraises his daughter’s illness as something he caused and uses avoidance as his coping strategy. The outcome may be the father does not provide adequate emotional support for his ill daughter).

Studies examining the relation between family burden and caring for a mentally ill family member are in fact usually assessing one or more factors in the stress-coping model. For example, the measure of burden used by Dyck et al. (1) assesses the economic impact incurred and the assistance provided to the mentally ill family member as well as “caregiver attributes” such as worry and affective response to illness. In the context of the stress-coping model these factors could be classified as stressors, mediating factors and appraisals. In a series of studies by Magliano and colleagues (4, 15, 17, 25, 26, 27) the measure of family burden assessed impact on work, financial problems, and constraints on social activities — potential stressors according to Szmukler et al. (6). In their burden measure, Magliano and colleagues also assessed feelings of loss, sadness, guilt and wanting to give up as well as worrying about the future and waking during the night factors characterized as outcomes in the stress-coping model.

Previous research indicates that assessing and understanding the families’ experience of caring for a mentally ill relative requires an approach that incorporates the multidimensional nature of the caregiving experience. As alluded to above, family psychoeducation as a clinical intervention clearly did not grow out of a framework that was based on a multidimensional conceptualization of the caregiving experience. The next section of this paper will briefly review family psychoeducation and discuss the barriers to implementation at both the programmatic and consumer level.

Family Psychoeducation

Treatment recommendations developed by the Schizophrenia Patient Outcomes Research Team (PORT) strongly endorsed the necessity of family psychoeducation (28). Specifically, the recommendations included the following: Patients who have ongoing contact with their families should be offered a family psychosocial intervention that spans at least nine months and provides a combination of education about illness, family support, crisis intervention and problem-solving skills training (29). The updated PORT recommendations include a similar statement (30). In addition, family interventions are proposed as supplements to medication treatment in order to decrease the level of caregiver burden (31).

Consistent with these recommendations, numerous family psychoeducation programs have been developed and tested over the last two decades. These programs are offered as part of a clinical treatment plan for individuals suffering from a mental illness (32). The main goals in working with the family of a person who is mentally ill are to accomplish the best outcome for the patient through collaborative treatment and to alleviate the burden of the family members by supporting their efforts to facilitate the recovery of the patient (16, 32, 33). Although these
models differ in format (i.e., multiple-family, single-family or mixed session), duration of treatment and therapeutic orientation (i.e., systemic, cognitive-behavioral), successful programs share the following key elements: (1) they regard schizophrenia as an illness; (2) they are created and led by mental health professionals; (3) they are offered as a treatment regimen that includes medication; (4) family members are included in treatment in order to facilitate change, not as “patients”; (5) even though family outcomes are important, the focus is on patient outcomes; (6) they do not include family therapies which suggest that behavior and communication in the family system cause the development of schizophrenia (28).

In addition to these key elements, treatment models shown to be effective required clinicians to adhere to specific principals in working with families of patients with schizophrenia. These principals include (a) the coordination of all treatment elements to ensure a collaborative and supportive relationship with all individuals working towards the same goal; (b) recognize the social and clinical needs of the patient and family; (c) explore the expectations that family members have about the treatment program and for the patient; (d) assess the strengths and limitations of the family’s ability to support the patient; (e) improve communication among family members; (f) provide training in problem-solving to the family; (g) encourage family members to expand their social support networks; and (h) provide the family with easy access to other professionals (32).

Although family psychoeducation programs that adhere to the schizophrenia PORT recommendations evidence positive effects in reducing patient relapse rates, relatives of individuals with schizophrenia continue to experience a dearth of services (28). Data from the PORT provide some insight into the status of services to families (29). For example, the interview field study questioned individuals diagnosed with schizophrenia about the amount of contact they had with members of their family and about the services their families received. Specifically, patients were asked, “Did anyone in your family receive information about your illness or your treatment or provide advice or support for families about how to be helpful to you?” Seventy-five percent of the patients had contact with their families; of those, only 31% reported that their families had received information, treatment, advice and/or support. In addition, 8% reported that a family member attended some kind of educational and/or support program about schizophrenia and treatment. These data are limited in that patients may not be aware of the services their family members may have received (34). However, although the schizophrenia PORT data may not provide rich and detailed information regarding the type and quality of services that families of patients with schizophrenia receive, the self-report and claims data does indicate that families of patients with schizophrenia are not accessing family interventions.

This deficit is surprising and concerning given empirical evidence suggesting that family interventions consistently and robustly reduce patient relapse and decrease perceived burden (3, 13, 19, 34). The results of a meta-analytic review conducted by Pitschel-Walz and colleagues (19) revealed that relapse rates of schizophrenic patients were reduced by 20% when relatives were involved in treatment. In addition, patients demonstrated significant improvement when family interventions continued for more than three months (mean effect size of .14 for interventions less than three months in duration compared to mean effect size of .30 for interventions longer than three months in duration; Z=2.36, p<.05). When family members were provided with information, advice, and support, less burden was reported (3). Similar to the results found by Pitschel-Walz and colleagues, a meta-analytic review by Cuijpers (13) indicated that personal and subjective distress, feelings of strain (d=.32), negative feelings towards the patient, rejection of the patient (d=.22), family conflict, and sense of family disruption (d=.39) were significantly less among family members involved in the patients’ treatment.

Based on the results of both meta-analytic reviews, it appears that when utilized, family psychoeducation is associated with positive outcomes for family members caring for a mentally ill relative. Yet, as previously stated, research also indicates that such services are under utilized. Barriers at the programmatic and consumer level may account for this phenomena (2, 32, 35). From the program, or administrative, level it is possible that mental health care providers a) do not recognize the usefulness and
importance of such a treatment approach, b) continue to work from theoretical perspectives that blame family dynamics for schizophrenia, and c) have concerns about the cost and length of family psychoeducation programs that range in length from nine months to two years (2, 28, 35). Amenson and Liberman (35) argue that such barriers result from a lack of implementation at the administrative level and the lack of reinforcement provided to clinicians for implementing family interventions.

At the consumer level, factors such as lack of transportation, competing demands for time and energy such as jobs, caring for very young children and lack of financial resources account for the fact that families who are most in need of educational and supportive interventions are underrepresented in the number of contacts made to mental health clinicians (32). In addition, and perhaps most relevant, family members report dissatisfaction with the mental health system in regard to availability of support, dissemination of information, access to clinicians, and inclusion in the treatment for the ill family member and therefore are hesitant to participate in family psychoeducation programs (34). In fact, it is possible that family members may be hesitant to engage in a psychoeducational program because they feel that the training will involve expectations for additional caregiving duties (32).

From the review of the literature, three points must be emphasized. First, the current conceptualization of the family burden constructs appears to neglect the multidimensional nature of the caregiving experience by defining “family burden” in terms of objective and subjective burden. Second, family psychoeducational interventions focus on patient well-being and may not sufficiently focus on caregivers appraisals, the range of stressors and mediating factors. Third, barriers to implementation of family services exist at both the programmatic and consumer level. However, a central theme of these barriers is that the multidimensional experience of caring for a mentally ill family member is not adequately addressed in existing services to families. In sum, our current conceptualization of caregiver burden, and family psychoeducational interventions based on such a conceptualization, does not incorporate the multidimensional family experience. Thus, a treatment approach that combines the multidimensional experience of caring for a mentally ill family member, effective coping strategies based on the caregivers experience, education regarding the illness and social support will likely yield the most optimal results.

New Directions — A Refocus on Caregiver Experiences in Family Treatment Approaches

As noted above, it appears that several factors impede families from accessing family-based interventions. Most notably, and pertinent to the present purpose, are those that involve the caregivers’ experience. As Szmukler and colleagues argue (6), caregivers report that they endure many demands on their time and resources — some demands that are related to the ill relative and some that are not. Regardless of the source of the demands, family members report that they do not access family-based interventions because they do not feel supported, they do not feel informed, nor do they perceive that the clinicians are available. An intervention that not only assesses what issues are troubling or “burdening” family members, but also: a) addresses how family members appraise the demands of caregiving, b) discusses how illness and non-illness related stressors and mediating factors influence the family members’ well being, and c) teaches effective coping strategies based on the caregivers appraisals and stressor could result in decreasing family members dissatisfaction with services and increase the degree to which family based services are utilized.

An intervention that provides such an approach are some family education models. This approach is an educational program created by families of mentally ill individuals to address their needs and advocate for system reform and is based on theories of stress, coping and adaptation. The National Alliance for the Mentally Ill (NAMI) and the Journey of Hope Program are two interventions that are led by trained volunteers from families of persons who have mental illness (28, 32). Similar to the goals and strategies of family psychoeducation programs, these 12-week courses combine information, skill building and support. However, while psychoeducation is generally clinic based, delivered by mental health professionals and primarily focused on the patient, family-
to-family education is community based and merges education with specific types of support to aid families through the various stages of understanding and coping with a family member's illness (28, 37). In contrast to family psychoeducation where the focus is on patient improvement, family-to-family interventions are primarily concerned with improving the well-being of caregivers. The reduced length of the program (12-weeks versus 9-24 months) and volunteer leadership also results in reduced cost of treatment when compared to family psychoeducation programs.

Results from a prospective naturalistic study suggest that families who participate in family-to-family programs report increased knowledge about the causes and treatment of mental illness, a better understanding of how to navigate the mental health system and improved well-being (36, 37). Specifically, family-to-family participants reported significantly greater empowerment at the family, community and service-system level after completion of the program (37). This intervention shows considerable promise and has facilitated participation in family psychoeducation programs (32). These findings have been replicated in prospective controlled study of family-to-family interventions (38). A blend of family education and family psychoeducation might provide the optimal benefit for both patients and families.

Conclusions

Over the last several decades the construct of family burden has been used to capture family members’ experience of caring for a mentally ill relative. The definitions and operationalization of this experience into subjective and objective components neglect the complexity and the multidimensional nature of the caregiving experience. In addition to problems operationalizing the caregiving experience, family interventions have also neglected to address the range of issues and concerns that impact those caring for mentally ill relatives. These two factors may be significant contributors to the under utilization of family-based services by relatives of individuals with schizophrenia. The development of more recent family interventions such as NAMI’s Family-to-Family and Journey of Hope are examples of treatment programs that do target the multidimensional nature of the caregiving experience. By incorporating such programs in conjunction with family psychoeducation interventions, we may achieve an optimal treatment approach that will allow families to more meaningfully engage in treatment. Therefore, as mental health programs and clinicians begin to design family interventions from a stress-coping framework, as was done with Family-to-Family and Journey of Hope and refine the intervention to better address different types of families, different situations and different time points throughout the course of the illness (37), family members may begin to feel that family-based services are appropriate and useful and therefore increase the degree to which they access services.

References


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