

# Family Functioning, Burden, and Reward in the Caregiving for Chronic Mental Illness

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*The burdens that caregivers for the chronically mentally ill experience are reviewed. Rewards that caregivers might experience have been understudied and the sparse literature is herein reviewed. The concept of expressed emotion, the importance of psychoeducation, and the role of family treatment are also reviewed, as they relate to the experience of the caregivers. Family conflict and family intimacy have been found to reflect the degree of burden or reward experienced and it is suggested that the family system, as the context within which the patient exists, be seen as the mediating environment for caregiving burden and reward. Family assessment, including a measure of the comfort with the role of caregiver and the extent of family support, is recommended in the assessment of caregivers. The family's ability to adapt over time is discussed as a measure of the family's ability to solve the problem of caregiving. Future directions for research are also presented.*

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“**R**adical changes in clinical practice require us to think differently about the interests of patients’ families. In the era of community care we expect much from them, but this has not been balanced by mapping out our duties towards them,” states Szmukler and Bloch (1997). This comment is the conclusion to an ethical argument for family involvement in the care of people with psychosis and is the sentiment behind the investigation of the role of the family in psychiatric illness; to improve both the care of the patient and the well-being of the family. It is also the belief of family systems thinkers that the patient both affects the family and is affected by the family; that the family within which the individual exists, functions as a system with actions and reactions, as components of the family changes, for example with the development of chronic illness.

While there have been many studies that look at the influence of family functioning on the course of illness of the chronically mentally ill patient, few investigators have considered the role of family functioning on the caregivers and their families. Fadden et al. (1987) reviewing the literature, commented that “despite their burden, relatives do not complain much, although they receive little support, advice, or information from the professionals engaged in treating the patient. Coping with their relatives’

problems frequently results in adverse effect on their own health, both physical and psychological.”

An overview of the nature of the caregiver burden experienced by families of the chronic mentally ill has been provided by Lefley (1996) who included extensive discussion of the services available and the services needed by this group of caregivers. An overview of family caregiving in chronic illness (Biegel, Sales & Schultz 1991) likewise reviews the experiences of the caregivers and the studies of burden, but in neither review is the family itself the main subject of review.

The family has a role in determining the outcome of the illness and it is imperative to study not just the patient, but the whole family more rigorously in order to understand more fully how the family influences outcome of illness and to understand the family's needs, burdens and hopefully rewards of caregiving. Appropriate interventions to maximize rewards and minimize the burden of caring for the mentally ill within the context of the family functioning can then be designed.

The purpose of this paper is to review the recent literature on the role of family functioning, both on the course of the patient's illness and on the burden and rewards reported by the family.

### **Family Functioning and the Course of the Patient's Illness: Expressed Emotion**

Expressed emotion (EE), the attitude of a relative toward a family member with a psychiatric impairment, was originally identified as a significant risk factor for relapse among schizophrenic patients (Brown et al. 1972). The researchers noted that those families that demonstrated high levels of criticism, hostility or emotional over-involvement, or high EE families, had patients that relapsed at four times the rate

of those families that measured as low EE, and did not demonstrate these traits. In a later treatment study, a 40% relapse rate at two years was recorded for those families who had additional family therapy versus 75% for those families without the additional family treatment component (Leff et al. 1990). Parker et al. (1990) reviewed studies up to 1990, and stated that at 9 months, the relapse rate for schizophrenia was 3-4 times greater for high EE families compared to low EE families.

Butzlaff & Hooley (1998) completed a meta-analysis of all available EE and outcome studies in schizophrenia, some 27 studies, and confirmed that EE is a “significant and robust” predictor of relapse in schizophrenia. In a related review of the literature in EE and mood disorders and EE and eating disorders, the mean effect sizes for EE in both of these diagnostic groups were significantly higher than for schizophrenia. EE appeared to be a stronger relapse indicator in patients with more long standing illnesses.

Researchers have looked at other outcomes and associations for EE. Woo et al. (1997) reported in a study of 45 adult schizophrenics and their family members, that high EE in family members was matched by more hostile and unusual behavior on the part of the patients.

King and Dixon (1996) have looked at the relationship between EE and social adjustment in 69 schizophrenics and their 108 relatives. They found that one component of high EE, emotional over-involvement, was associated with a better social outcome in patients. The critical comments component did not show a relationship with social adjustment.

MacMillan (1986) found that emotional over-involvement was rare in first episode schizophrenic patients, although the interpretation of this finding is open to question because of several deficits in this study, for example, the family's perception

of the patient's illness was not taken into account. Nevertheless, the conclusion that emotional over-involvement may not develop until the illness becomes chronic is intriguing, suggesting that EE is a measure of some fluidity and a measure of family process, rather than family trait.

Brewin et al. (1991) studied the attributions that relatives made about their sick relative and found that high EE relatives attributed the abnormal behavior of the patient to internal sources within the patient's control, with comments like, "He's just lazy." This could in part be the result of a lack of understanding about the illness, and would explain the good results in patient's long term outcome with psychoeducational interventions (see below). Kavanagh (1992) also has suggested that high EE occurs in families who know less about schizophrenia, especially with negative symptoms, and attribute these to the patient's laziness rather than the illness. He discusses the difficulty in dealing with the family's entrenched attitudes about the patient and suggests that this may be based more on unresolved grief rather than the family's stubbornness or lack of understanding or compassion.

Stirling et al. (1993) followed 30 first or early admission psychotic patients and their relatives over 18 months and found that there was no correlation between initial EE ratings and 18 month ratings. They did find a relationship between high EE and relapse but found that the internal components were different as time passed, with over-involvement giving way to marked criticism. This again suggests that EE is not a stable state construct, but a fluid process measure.

Measurement of EE has been attempted with other disorders. Hooley and Teasdale (1989) found in depressed patients and their families, that a single self report rating of the amount of criticism received from the relative predicted relapse more strongly than the long EE interview

(Camberwell Family Interview). In a study (Hooley et al. 1986) of depressed patients, 59% with high EE spouses relapsed at 9 months compared to none in the low EE family group. Hooley et al. (1998) have also found that high EE is correlated with good outcome in the families of patients with borderline personalities. In a study of 23 bipolar patients, high EE was found to be predictive of relapse at 9 months after discharge for acute mania (Miklowitz et al. 1988).

Researchers have begun to tease apart the concept of EE to try to elucidate the mechanisms and to try to understand how this dimension of family functioning develops and how it predicts illness course. Cook et al. (1989) studied 48 disturbed adolescents and their families, and they found that high EE mother-child dyads constituted more tightly joined emotional systems than low EE dyads, and that adolescents in high EE dyads had a more oppositional style of responding. Of interest, they found that the high EE dyads were characterized by a bi-directional mode of relating, describing the mother and adolescent as entrained by each other's affect.

The data presented here suggests that a more complex transactional model is needed to try to understand how family attitudes evolve during the course of a relative's schizophrenic illness. The concept of EE has turned out to be a highly complex structure. Each of its components measures different aspects of family functioning and includes structures not clearly identified by the primary investigators. The close examination of family interactions outlines the fact that EE is a transactional process that may originate in the patient's disruptive behavior. These transactions build up over many years of chronic illness and can be viewed as a developmental process, part of the adaptation to chronic illness. If adaptation is problematic, then EE will be high and predictive of relapse of

the patient. EE appears to be, not a trait of the family, as was originally thought, but rather a process of family dysfunction. As the concept of EE is teased apart, and it is seen to be a function of family transaction, then other measures of family functioning may prove useful to clarify which dimensions of family functioning are operating during the different stages of the family's adaptation to chronic illness. As described above, emotional over-involvement may be a prominent feature at initial presentation and criticism of the patient may occur at later disease stages. Both of these maladaptive responses will result in high EE rating of the family, although the family transactions are different. It is important to know what the underlying mechanisms are in order to develop effective and focused treatment plans that deliver only the interventions that are needed at that stage in the family adaptation.

Missing from the EE literature is measurement of family burden and reward. In a study of daughters of people with dementia, Bledin et al. (1990) found that high EE daughters reported more strain and distress than low EE daughters. Incorporating measurements of burden and reward into the work with families of the chronic mentally ill may allow us to further understand their adjustment and coping styles.

When a family assessment occurs is important. Early after diagnosis of illness, families are in acute crisis or may be in denial about the presence of severe psychiatric illness. The psychiatrist may also not be able to clearly diagnose the condition or not be willing to commit to a diagnosis especially in adolescence or early adulthood, or may not wish to upset the family by giving a diagnosis, thus prolonging the period of uncertainty. Time is also required for families to understand the impact of diagnosis, both on their relative's future and also on the family's

caregiving responsibilities. Measurements of family dysfunction, like EE, at an initial time, will have a different meaning from measurement at a later more chronic stage of the illness. The studies described above bear this out.

If we want to measure more than EE, what aspects of the family should we be assessing? It could be thought that a family needs to have good problem solving skills and to have an overall high level of functioning in order to develop the skills to care for a sick relative, but this is not known. If problem solving can be shown to be a key variable, then interventions that focus on teaching the steps of problem solving would be appropriate. One model of assessment and therapy, the Problem Centered Systems Therapy of the Family (Epstein and Bishop 1993) is ideally suited to assess a broad range of family functions and to develop a treatment approach tailored to the strengths and weaknesses of the family. This model assesses affective involvement, affective responsiveness, roles, communication, behavior control, and problem solving. Application of this model to the task of assessing caregiver burden and reward is currently underway. Other measures of family functioning that may be applicable in this situation include the family hardiness index (FHI) (McCubbin et al. 1993) that measures family transition crises and adaptations for acute and long-term stressors, or the self-report family inventory (SFI) (Beavers & Hampson 1990) that allows measurement of family functioning across several domains, such as competence, cohesion, leadership, and emotional expressiveness.

### **The Importance of Family Psychoeducation in Reducing Relapse Rates**

The patient advocacy groups such as the National Alliance for the Mentally Ill and the Manic-depressive and Depressive

Association, have focused on the support and education of the families of the chronic mentally ill, with psychoeducational programs such as the Journey of Hope sponsored by NAMI in the Rhode Island branch. These interventions are based upon the growing evidence that psychoeducational approaches are associated with a reduced relapse rate for chronic mental illness. The evidence for schizophrenia is described by Leff et al. (1985) and for bipolar disorder by Miklowitz and Goldstein (1997). In addition, McFarlane et al. (1995) studied psychoeducational family therapy, comparing single and multi-family group treatment over four years with schizophrenic patients and their relatives. They reported a 50-57% relapse rate at four years with multi-family group therapy vs. 78% relapse rate for single family therapy. Several suggestions were discussed for this higher wellness rate for the multi-family group such as cross-parenting, communication normalization, crisis intervention, and more effective problem solving.

Intervention strategies aimed at reducing EE have been shown to reduce relapse rates for schizophrenia, but it is unclear how long contact with these families needs to continue and whether or not non-specific factors may contribute to the reduced relapse rates. Anderson et al. (1986), Falloon et al. (1984) and Piatkowska et al. (1992) have provided detailed treatment manuals that also include communication training and problem solving techniques. These studies include mechanisms beyond psycho-education and have pointed the way to enlarging the study of intervention with families of the chronically mentally ill into a more dynamic and transactional form in order to both reduce relapse in the patients and to improve the general family functioning.

It is unclear whether or not these interventions reduce family reports of burden or increase reward.

## Treatment

Treatment issues are a new variable that now needs to be taken into account in caregiver research as more families are involved in self-help groups or in specific treatment situations. Family involvement in treatment has taken many forms over the years. The initial work of family therapists tended to blame families for causing the illness of their relative. Family education, at a basic level, means providing information to families about illness usually in a few sessions. The types of interventions that are now well researched as effective in the treatment of chronic mental illness are family psychoeducation treatments that provide intensive training and coping skill enhancement with long-term support and guidance.

Bloch et al. (1995) looked at the health of families caring for schizophrenic relatives and reported on intervention with these families who were given six 1-hour, weekly sessions. These sessions were individualized and focused on enhancing coping skills. They found that a broad range of interventions were needed in order to meet the needs of these families, above and beyond psycho-education and reducing family EE. Thirteen themes of concern were noted and covered a wide range of personal, social and family dimensions.

Three main themes were identified:

1. The caregivers were involved in multiple caregiver roles, providing help not only to the schizophrenic relative, but also to one or more other family members of the immediate or extended family who suffered from physical or mental illness or had an intellectual disability.

2. Conflict about how to manage the patient with members of the family disagreeing about treatment options and other family responsibilities.

3. Criticism or lack of acknowledgment by other family members about the caregivers' efforts.

## BURDENS AND REWARDS IN CAREGIVING FOR CHRONIC MENTAL ILLNESS

### Burden

Burden is a loose construct that has been defined in various ways, but usually includes measures of subjective and objective distress as well as measures of the way in which a caregiver's life-style has been altered by financial difficulties, curtailed social activities, loss of vacations etc. Bloch et al. (1995) also identified in the caregivers, feelings of loss and grief, guilt over the transmission of the illness, a sense of hopelessness, and a feeling of not doing enough. Significantly, 93% of the caregivers described an intense need to share experiences with others. Other burdensome themes related to confusion about whether the patient's behavior was related to illness or personality. They concluded by stating that; "current approaches to family intervention probably lack the scope to meet such an array of needs." These themes have been discussed in depth in the dementia caregiver literature and only recently among caregivers of chronic mental illness, although their concerns and burdens may be similar. In the dementia caregiving literature of over five years and reported in virtually all studies, there were elevated levels of depression for the caregiver (Schultz et al. 1995). The predictors generally known to be risk factors for negative health outcome emerged in these studies, with few variables being specific to dementia. The general risk factors for negative health outcome are financial problems, lack of social support, low caregiver self-esteem and mastery and poor health. Two specific findings related to caregiving for the demented elderly were, patient problem behaviors and patient cognitive

impairment. Schultz concluded that the researchers in dementia caregiving needed more complex models of family functioning as the majority of patient characteristics and caregiver contextual variables are not consistently related to caregiver health outcomes. This comment echoes the remarks of the family researchers described above in the study of EE and family functioning.

Application of the extensive work on caregiver burden in the dementia population would contribute a great deal to the understanding of the burdens of the caregivers of chronic mental illness.

*Objective burden* is defined as observable concrete costs to the family resulting from mental illness, e.g., disruption to everyday life in the household and financial loss. *Subjective burden* is defined as the individual's personal appraisals of the situation and the extent to which people perceive they are carrying a burden. The association between objective and subjective burden is complex.

Measuring objective burden is relatively straightforward. Platt's (1983) Social Behavioral Assessment Schedule (SBAS) is commonly used. Robinson's (1983) caregiver strain instrument offers a short 14-item diverse measure of objective burden or strain.

Subjective strain scales, generally include personal attitude, physical and psychological health items, family relationship items, and social support items. Burden or strain scales offer combined objective and subjective items, but using a single scale does not allow the relationship between objective and subjective burden to be examined, although many measures allow separate analysis of items that correspond to objective and subjective burden.

Maurin & Boyd (1990) have presented a critical review of the association between objective and subjective burden and the mediating factors between them,

suggesting that the patient family relationship acts as one of the mediating factors between objective and subjective burden. Schene et al. (1996) emphasizes the need for standardization both in the definition of burden and in the measurement of burden. Reviewing all the caregiver instruments and abandoning the label "burden," Szmukler et al. (1996) developed a 66-item Experience of Caregiving Inventory (ECI) to reflect their adoption of a stress appraisal coping model of caregiving, and to include a measure of reward. Out of the 10, there were 2 positive subscales asking about positive personal experiences and good aspects of the relationship. However, these subscales did not have predictive value.

Schofield et al. (1997) likewise have developed a comprehensive instrument to assess the experience of caregiving, both positive and negative. Their items were drawn from the instruments available and exploratory interviews, and their subscales demonstrated a satisfactory reliability. This instrument offers two advantages over prior instruments. It offers more opportunity for expression of reward/satisfaction, and is relevant to a broad range of ages, levels, and types of disabilities. The instrument can be used as a whole or in part.

The concept of burden as applied to chronic mental illness may be problematic in that many family members may consider the term burden to be offensive and seen as rejection of their family member. Thus Lawton's term of caregiving appraisal, that includes burden and reward, may be used as a more acceptable term. Lawton et al. (1989) measured caregiving appraisal by analyzing the responses of 632 caregivers, and described three clear dimensions. These were subjective burden, caregiver impact (objective burden) and caregiver satisfaction. They reviewed data that suggested that caregiver mastery was a dimension that should be operationalized

in future caregiver research. (This dimension can be conceptualized as problem-solving.) Lawton also recommended that future research include assessment of the quality of the relationship between the caregiver and the identified patient.

In a study of 125 family caregivers of patients who had been discharged from the three state psychiatric hospitals in Cleveland, Ohio, Thompson and Doll (1982) found that while there was a significant relationship between objective and subjective burden, in most families a disparity suggested that some families did show resilience, in that high objective burden did not necessarily result in, or was not necessarily associated with high subjective burden. This resilience may have been experienced as reduced burden or as reward in caregiving. Subjective burden has been found to be a more powerful predictor of distress than the patient's symptomatology or the objective burden of the caregiver (Noh & Avisan 1988).

Despite recognition of the distress that families experience, the specific determinants of family burden are not well understood. It is also important to look at the incidence of depression in the caregivers as well as other psychiatric and physical sequels associated with caregiver stress. In a community study of 103 relatives of chronic mentally ill patients, higher levels of burden were associated with increased depressive symptomatology for the caregivers (Song et al. 1997).

The severity of patients' symptoms is the only variable that has been shown to have a strong association with burden, although this relationship is not simple. This finding is from the dementia literature (Schultz et al. 1995) and has not been studied so extensively in the chronic mentally ill. In a study of 134 members of a self-help group for relatives of schizophrenics, a mail-in self report survey showed high levels of psychological distress compared with test

norms and considerable burden due to "turbulent behavior" (Winefield and Harvery 1993) after controlling for the caregivers age, sex and social supports. Those caring for female sufferers reported greater distress than those caring for male sufferers. The caregivers for these female patients were spouses (15.6%) and siblings (18%). The caregivers for the male patients were parents (92%), usually the mothers. The adequacy of family support was associated with caregivers' lower psychological disturbance, negative affect, and emotional upset. Older caregivers reported less negative affect and older and female caregivers reported less burden. Those with longer illnesses also had less disturbed caregivers. Overall, the caregivers reported that caregiving disrupted their lives, most frequently social activities (44.8%) and family relationships (44%). Those caring for female patients constituted the caregivers at highest risk for burden.

The issue of gender is complex as most studies have not differentiated between the stage of the illness, the developmental stage of the family and the relationship between caregiver and patient i.e. mother-son, which is common in schizophrenia, or male spouse of female patient with chronic depression etc. Women have higher levels of psychological complaints in the community in general and men tend to under-report symptoms. Women and men view the activity of caregiving differently, often performing different tasks and having different levels of interest in the caregiving role. Financial concerns and wage earning capacities are also important variables, as men may continue to work and employ others (family members or professional caregivers) to carry out the tasks. However, Finley (1989) studied adult children as caregivers for elderly parents and found that in every task, caregiving females are more likely than males to provide care. Females are considered the more 'natural'

caregivers as an extension of the social and mothering roles.

In a study of caregivers for an Alzheimer patient, (Parks & Pilisuk 1991) male caregivers' higher anxiety levels were predicted by lack of social support and the use of fantasy and withdrawal as a dominant coping mechanism. For female caregivers, internalization was a coping skill that predicted feelings of resentment. The social role expectation of each gender will also affect the response to the caregiving situation. The rewards of caregiving may be extensive and may differ for each gender and clearly require further study. In our pilot study, elderly male caregivers often remark on how rewarding caregiving is and may reflect their desire and ability to 'give back' nurturing that they perceive their spouses to have given them over the years.

Patterson et al. (1990) studied 30 caregivers for older psychotic patients and found female spouses reported more losses related to past and anticipated life styles. Spouses comprised 40% and described more role captivity (a feeling of being trapped in an unwanted role) and perceived little or no capacity for change. Cook et al. (1994) studied family burden in 222 parents of offspring with severe mental illness and found that the type of burden varied with the age of the caregiver; older parents being troubled by cognitive dimensions of burden while younger parents were distressed by the offspring's behavior.

In summary, objective burden is a clearly defined measure, but subjective burden depends upon many variables both in the patient and in the caregiver. These variables modify the objective burden and allow for the experience of reward in caregiving. Examples of these variables may include the relationship between the caregiver and patient, the expectation and comfort with the role of the caregiver, the social supports, financial resources, the health, gender, and age of the caregiver,



and the other responsibilities of the caregiver. Measurement of burden must then include measurements of these variables in order to get a truer assessment of these subjective burdens and rewards of caregiving.

In order to clarify the nature of these modifying factors, it would be necessary to do a full family functioning assessment. Only then could further measurements be added to the caregiver burden instruments.

### **Reward**

Bulger et al. (1993) in a study of 60 caregivers for adult children with schizophrenia, recruited from the South Carolina Alliance for the Mentally Ill, found that the respondents quite frequently experienced caregiving gratification and intimacy with their adult child, and reported little burden or conflict. No subjects reported complete absence of gratification. The caregivers reported more gratification and intimacy than burden and conflict. The caregivers had low scores on objective burden, indicating that they provided only minimal assistance with daily activities and did little to help their children control behavior that was assumed to be upsetting for caregivers. The patients' symptoms were scored on a modified clinical rating scale and represented thirteen psychopathological behaviors. They did find correlations between caregiver burden and family conflict, and reward or gratification correlated with family intimacy.

They hypothesized that the respondents might minimize the degree of burden that they might experience by denial, accommodation to the role of caregiving, and a wish to avoid being seen as complainers. The caregivers were recruited from a support group/organization, and as described above, this association may be important in reducing burden and maximizing reward. Another finding in this study was that those caregivers who were more disadvantaged by income, education, formal support, and racial/minority status reported being happier with

their caregiving role than those who were more advantaged in these respects. The authors suggested that this may be related to income/disability payments, however, this is only conjecture and this finding requires further investigation.

In a related study on the relationship between intimacy and EE (Fearon et al. 1998), low levels of intimacy were correlated with high EE in the caregivers of Alzheimer patients. Intimacy was defined as comprising of the elements of affection, cohesion, expressiveness, compatibility, and conflict resolution, all components of family functioning. Interestingly, 24 of the 100 dyads assessed, showed increased intimacy, supporting the view that caregiving as a role can be rewarding.

A study of family caretakers for long standing chronic mental illness (Spaniol et al. 1987) reported that 67% of family members (primarily parents) reported that they were managing adequately or better over time. Hatfield (1981) followed 30 parents of older offspring and also reported improved coping over time. These studies reported less burden, but did not address the issue of reward.

In summary, reward has been inadequately studied in this population and in those studies that do exist, definite reports of reward are found. The findings that family conflict is associated with burden and that family intimacy is correlated with reward may be the key to understanding why some families cope better than other families. The role of support groups is also very important and may constitute a significant component of successful treatment by assisting the caregivers in a variety of ways.

### **CONCLUSION**

The role of the family in the course of illness has been extensively studied, with the construct of expressed emotion being prominent.

Researchers are now turning to the study of the caregivers of the chronically mentally ill. This reflects the need for adequate understanding of the pressures for family caregivers as society expects that these patients be cared for in the community, rather than institutions. Burden and reward are relatively new concepts to the chronic mental illness research with families and looking at the literature for caregivers for dementia patients can provide us with some direction for research in the caregivers for chronic mental illness. While there are many differences between these populations, there may be some similarities, with role changes and changes in affective involvement being prominent. Schultz et al. (1995), in a review of the caregiving literature in dementia, stated that the evidence linking psychiatric health effects and dementia caregiving is robust, with depressive symptoms being prominent. They also found that predictors generally known to be risk factors for negative health outcomes emerged in these studies with financial stress, life satisfaction, perceived stress, and self-esteem being significantly related to psychiatric morbidity. They reported two specific findings that influence the caregiving experience; patient problem behaviors and patient cognitive impairment. In conclusion, they expected that the next generation of caregiving studies would look at complex models of multiple risk factors on caregiver outcome. I consider the family system to be the ideal complex model/environment in which caregiving occurs and hence the natural area of investigation for the caregiver researchers.

The prominence of organizations like the National Alliance for the Mentally Ill encourages families to take an active role in the management of their relative and to bring political pressure to bear both locally and nationally. Psychoeducational approaches to treatment are helpful, but

most of these therapies involve more than psychoeducation, especially if held in multi-family group settings. It is unclear if these groups are teaching skills that help to develop positive adaptational behaviors and attitudes, provide support, normalize communication, reduce EE, or all of the above. It is not known what the content of these sessions should be, with each school tailoring the content to their model of treatment and it is not known how many sessions are needed nor at what intervals. Are booster sessions needed?

The predictors of caregiver burden as determined from the literature so far are male gender, lack of family support, and younger age. It has also been shown that caregivers are at increased risk for depression. Role captivity and the responsibility of multiple caregiving roles, family conflict about caregiving, and criticism or lack of acknowledgment by other family members are some of the family factors so far identified that increase perceived burden. To study gender in relation to caregiving, the relationships of caregiver to patient and the expectations that accompany that relationship i.e. spouse/parent/sibling, need to be evaluated. The social role expectation and life style of the family are important in determining the adaptation the caregiver makes. Mothers of younger adults and elderly male spouse caregivers experience different burdens and may experience different rewards in caregiving.

The measurement of family functioning is seen as crucial, especially in light of Bulger's study which suggests that the experience of burden is related to family conflict and that the experience of reward is related to family intimacy.

Family intimacy may facilitate communication and hence the opportunity to problem solve and facilitate the tasks and maximize the rewards of caregiving. In a family that is conflicted, the ability to communicate is impaired and the

opportunity to problem solve is impeded. The potential for minimizing burden and maximizing reward is therefore lost. It is possible that a conflicted family is unable to recruit family support, thus isolating the caregiver and increasing burden. Increased social support is known to reduce burden (Potasznik & Nelson 1984, Crotty & Kulys 1986). Thus, reducing family conflict may reduce burden. Research on the effect of family therapy could test this hypothesis. It is suggested that the family system, as the context within which the patient lives, be seen as the mediating environment for caregiving burden and reward.

It is suggested that over time, caregivers can adapt and can experience rewards from caregiving, but sample bias may be present by selecting these families from support groups. Another way to look at this data is to consider that support groups do enhance coping skills, reduce burden, promote good coping skills, and allow acknowledgment of reward, but these findings do require validation and comparisons with families from other settings.

The future direction for caregiver studies in the chronically mentally ill includes longitudinal studies from time of diagnoses through the early adjustment years, into the middle chronic phase and then into the later phase of illness, when elderly caregivers think about their own mortality and look to others, possibly other family members for help with caregiving. The family life cycle has to be taken into account.

It may be that the family's response to mental illness occurs in recognized stages, although the process of adaptation may vary from family to family. The role of unresolved grief in the 'loss' of that relative with illness may play a yet undefined role in the adaptation of the caregiver (Miller 1990), as may the role of stigma and the possible concealment of the sick relative.

Sample populations need to be drawn from all demographic and socioeconomic

groups and compared to the easily studied patients and families drawn from the self-help groups.

Most importantly, family functioning needs to be measured, especially roles and affective involvement. The EE concept has been useful for many years, but the families need an opportunity to express the burdens and rewards related to caregiving. Assessment of family functioning will allow measurement of the family's ability to problem solve and family intervention can then be tailored to the specific strengths and areas of dysfunction in the family. A new direction in family assessment and the assessment of burden and reward will bring specificity and increased understanding to the field which has up until this point, been vigilant and effective in improving the outcome for the chronically mentally ill patients. It is now time to place the same effort and concern into the study of the context within which the patient lives—the family system.

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