Predictors of Distress and Hope in Relatives of Individuals with Schizophrenia

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Predictors of Distress and Hope in Relatives of Individuals with Schizophrenia

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Data was collected at McLean Hospital in Belmont, Mass., U.S., and the Freedom Trail Clinic Schizophrenia Research Program in Boston, Mass., U.S.

Abstract: Background: The present study was conducted to examine factors that may be targeted by psychoeducation programs in order to reduce distress and increase hope in family members of individuals with schizophrenia. Method: Using separate stepwise multiple regressions, we examined the relationships among 51 family members’ reactions to a loved one’s illness (adaptive and maladaptive coping strategies, criticism, overinvolvement, and blaming attributions) and distress and hope. Results: Maladaptive coping strategies significantly predicted more distress and less hope in participants. Further stepwise regressions examining the relationship between distress and hope and subgroups of maladaptive coping revealed that mental disengagement was a significant predictor of more distress and behavioral disengagement was a significant predictor of less hope. Conclusions: These results suggest that recovery-oriented psychoeducation programs that help family members remain engaged with their relatives and work through problems (rather than resorting to mental or behavioral avoidance) may be especially helpful for reducing distress and increasing hope in caregivers of the mentally ill.

Introduction

Schizophrenia is a debilitating mental illness that takes a toll not only on the person who suffers from it, but on family members as well, resulting in high levels of distress and caregiver burden (1–3). Family members commonly experience an array of difficulties including: grief over losses experienced by the client, shock and disbelief over witnessing bizarre symptoms in a loved one, difficulties accessing treatment resources, family disruptions caused by the illness and demands of caregiving, financial stress caused by lost time from work and unreimbursed medical expenses, restricted leisure and social activities, and feelings of stigma (3). Reducing family burden and distress is an important treatment goal in order to improve the quality of relatives’ lives and decrease family stress.

A major goal of family psychoeducation programs for schizophrenia led by mental health professionals is to reduce distress and burden (4–6). However, research on the impact of these programs on family functioning has produced mixed results, with some studies reporting beneficial effects on burden and distress (7–9), but not others (10–12). There is clearly a need to develop family psychoeducation programs that are more effective at alleviating the impact of the illness on families.

One approach to improving the effectiveness of family programs is to better understand the determinants of caregiver distress and burden, especially potentially malleable factors that could be
targeted for change. Several caregiver factors may be good candidates to target for change, including coping styles, attributions about the causes of disturbed behaviors of a relative, stressful attitudes and behaviors towards the relative (i.e., expressed emotion), and hope. We briefly review research on these factors below.

Coping Style. Folkman and Lazarus (13) define coping as cognitive and behavioral efforts to manage specific demands that are perceived to exceed an individual’s resources. According to Folkman and Lazarus’s stress-coping model, when people are confronted by a stressful situation (e.g., a loved one displaying upsetting symptomatic behaviors), they evaluate it (e.g., “This situation is hopeless and I can’t deal with it”), and then the outcome of this appraisal determines their emotional and behavioral responses to it (e.g., withdrawing from their loved one, using alcohol). Stress occurs when an individual’s appraisal of a situation leads them to believe that the demands of it exceed their coping resources. According to this model, stress may be reduced when people are able to improve their coping skills.

Research on the association between coping styles and burden in relatives of individuals with schizophrenia has found that use of coping strategies that emphasize constructive action (i.e., problem-focused techniques) tend to experience less burden and distress (14, 15). In contrast, coping strategies such as resignation, denial, and avoidance have been associated with higher levels of burden (15, 16). In addition, reduction in avoidant coping styles of caregivers has been found to be associated with lower levels of burden over time (17).

Expressed emotion. A large body of literature indicates that expressed emotion (i.e., relatives’ relationships with clients characterized by a high degree of criticism or emotional overinvolvement, such as extreme self-sacrificing behavior) is associated with a more severe course of schizophrenia and other psychiatric disorders (18). Relatives with high expressed emotion, as assessed with a semi-structured interview with the family member (19), tend to display verbally negative behaviors towards the client during interactions and/or become highly overprotective and intrusive. Based on the stress-vulnerability model of schizophrenia (20, 21), these reactions are thought to produce interpersonal stress that triggers relapses of psychotic symptoms in schizophrenia.

Greenley (22) has suggested that expressed emotion represents an ineffective coping strategy in which caregivers react to their concerns by attempting to exert social control over their relative. A few studies have found that high expressed emotion is associated with greater family burden (23, 24). A reduction in expressed emotion has also been associated with reduced burden nine months following hospital discharge (25).

Attributions of illness-related behaviors. Hooley et al. (26) suggested that differences in caregivers’ attributions regarding their relatives’ ability to control their illness may be related to their expressed emotion. Specifically, attributions by caregivers of greater responsibility and blame of the client for his or her symptoms were predicted to be associated with higher levels of expressed emotion, which has been supported by several studies (27–30), with clients most likely to be held responsible for negative symptoms (29) and substance abuse (31–33).

Attributions of an individual’s responsibility for his or her illness may contribute to caregiver distress or subjective burden to the extent that they perceive their relative as willfully imposing on their time, energy, and money. However, little research has examined this relationship. Barrowclough, Tarrier and Johnston (34) did not find an association between caregiver distress and beliefs about their relative’s responsibility for illness-related problems, although they did find that distress was associated with greater self-blame among the caregivers.

Hope. Historically, schizophrenia has been characterized as a chronic illness with a poor outcome (35), with little hope given to clients and families for improved functioning and quality of life. However, there is now strong evidence that many individuals with schizophrenia experience partial or complete symptom remissions over the long-term (36, 37). Furthermore, advances in rehabilitation approaches such as supported employment (38),
social skills training (39), and teaching illness self-management skills (40) provide a solid basis for hope for the long-term outcome of schizophrenia.

The improved outlook for schizophrenia, combined with a call for a shift in the focus of treatment away from symptom remission and towards helping individuals rebuild meaningful lives, has led to the “recovery movement,” initially championed by mental health consumers, but since widely adopted by professionals and policy makers. This focus on restoring functioning and helping individuals develop a sense of purpose has also drawn attention to the importance of instilling hope for improvement and recovery from psychiatric illness, in both that person (41, 42) and the people around them, including family, friends, and treatment providers (43, 44).

Family members may be particularly vulnerable to low levels of hope (45, 46). A recent study found that hope in family members of individuals with OCD was associated with lower depression and use of denial or disengagement coping strategies, and positively related to active reframing and use of social support coping strategies (47). Several authors have written about the importance of hope for relatives of individuals with schizophrenia based on relatives’ narratives and practitioners’ observations (48–50). Also, hopelessness is a key feature of depression (51, 52). However, more research is needed to understand the relationship between family members’ hopefulness about their relatives’ future and distress.

Present study
The present study was conducted to examine the predictors of distress and hope in family members of people with schizophrenia in order to identify factors that could be targeted in family psychoeducation programs. Based on the literature reviewed above, we hypothesized that greater use of adaptive coping strategies (e.g., active coping, seeking emotional support), less use of maladaptive coping strategies (e.g., avoiding the client, denying the problem, etc.), less emotional overinvolvement and criticism, and less blame of the client would predict lower levels of distress among family members and greater hope about the client’s future.

Methods
Participants
The study included 51 participants (from 34 families), who were self-identified adult relatives of individuals with schizophrenia or schizoaffective disorder. Participants were recruited from fliers and referrals from McLean Hospital in Belmont, Massachusetts, and the North Suffolk Mental Health Association Freedom Trail Clinic in Boston, Mass. All participants were interviewed as a part of a controlled study investigating the efficacy of a family psychoeducation program (53). Interviews took place at the participants’ initial visit, before they were assigned to the psychoeducation program or a waiting list. This study was approved by the Institutional Review Boards (IRB) of McLean Hospital and the Massachusetts Department of Mental Health.

All participants were informed of the research procedures and provided signed informed consent. In addition, as a requirement of the IRB at McLean Hospital, the ill relatives of family members provided signed consent for their family member to participate in the study.

Eligibility criteria for the study were: 1) at least one relative with schizophrenia or schizoaffective disorder, 2) age 18 or older, and 3) no reported history by participant of schizophrenia or schizoaffective disorder. Client psychiatric diagnosis was based on either the report of the treating clinician who referred the relative to the family program or a screening interview with the family-member participant about their relative. Up to three relatives per family were allowed to participate (independence of data from within families is addressed in the results section). Demographic characteristics of the sample are presented in Table 1.

Measures
Distress
Burden was assessed with the Burden Assessment Scale for Families of the Seriously Mentally Ill (54), a 19-item self-report measure. Subjects are asked to rate each item on a 4-point Likert scale, with higher numbers indicating greater burden. The items
Depression was assessed with the Beck Depression Inventory (55), a widely used 21-item self-report measure, in which the items are added to form a total score. Cronbach’s alpha in this sample was .87.

Anxiety was measured with the Beck Anxiety Inventory (56), a 21-item self-report measure in which the items are added to form a total score. In this sample, Cronbach’s alpha for the scale was .89.

Worry was assessed with the Worry Subscale of the Family Burden Interview Schedule – Short Form (57). The Worry subscale asks participants about seven dimensions of worry rated on a 5-point Likert scale and items are added to form a total score. Cronbach’s alpha for this scale was .71.

Hope
An item from the Schizophrenia Knowledge Test (58) was used to assess participants’ hopefulness about their relative’s future. Participants were asked to answer the question, “In general, how hopeful are you concerning your relative’s future?” using a 7-point Likert scale ranging from 1 (not hopeful) to 7 (very hopeful).

Reactions to relative’s illness
Family members’ coping styles were measured using modified versions of several subscales of the COPE Inventory (59). The COPE was developed to assess a broad range of coping responses to stressful events or situations, and includes responses thought to be functional as well as responses thought to be dysfunctional. The COPE was designed to measure either trait coping (usual coping styles) or to measure coping over a specific time period. For this study, coping behaviors over the past month were assessed. Several items were re-worded to refer specifically to coping with a relative’s mental illness, rather than difficult or stressful events in

Table 1. Characteristics of the Study Sample (N= 51)

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
<th></th>
<th>N</th>
<th>%</th>
</tr>
</thead>
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<td></td>
<td></td>
<td>Ethnicity</td>
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<td></td>
<td></td>
<td>African/</td>
<td>2</td>
<td>3.9</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td>Asian-American</td>
<td>1</td>
<td>2.0</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Mixed</td>
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<td></td>
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<tr>
<td>Relationship to patient</td>
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<td></td>
<td>Highest education level</td>
<td></td>
<td></td>
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<tr>
<td>Mother</td>
<td>27</td>
<td>52.9</td>
<td>Advanced degree</td>
<td>20</td>
<td>39.2</td>
</tr>
<tr>
<td>Father/ Stepfather</td>
<td>14</td>
<td>27.4</td>
<td>4-yr college graduate</td>
<td>19</td>
<td>37.2</td>
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<tr>
<td>Sibling</td>
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<td>5.9</td>
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<td>Some high school</td>
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<td>2.0</td>
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<tr>
<td>Living with patient?</td>
<td></td>
<td></td>
<td>Gender of patient</td>
<td></td>
<td></td>
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<tr>
<td>Yes</td>
<td>29</td>
<td>56.9</td>
<td>Male</td>
<td>22</td>
<td>64.7</td>
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<td>No</td>
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<td>43.1</td>
<td>Female</td>
<td>12</td>
<td>35.3</td>
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<tr>
<td>Marital status</td>
<td></td>
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<td>Years since diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/ living</td>
<td>40</td>
<td>78.4</td>
<td>1 yr</td>
<td>8</td>
<td>23.5</td>
</tr>
<tr>
<td>with partner</td>
<td>2</td>
<td>3.9</td>
<td>1–2 yrs</td>
<td>10</td>
<td>29.4</td>
</tr>
<tr>
<td>Single</td>
<td>8</td>
<td>15.7</td>
<td>2–5 yrs</td>
<td>5</td>
<td>14.7</td>
</tr>
<tr>
<td>Divorced/ separated</td>
<td>1</td>
<td>2.0</td>
<td>5–10 yrs</td>
<td>4</td>
<td>11.8</td>
</tr>
<tr>
<td>Widowed</td>
<td></td>
<td></td>
<td>10 yrs</td>
<td>7</td>
<td>20.6</td>
</tr>
</tbody>
</table>

are then added into a total score. In this sample, Cronbach’s alpha for the scale was .86.

Depression was assessed with the Beck Depression Inventory (55), a widely used 21-item self-report measure, in which the items are added to form a total score. Cronbach’s alpha in this sample was .87.

Anxiety was measured with the Beck Anxiety Inventory (56), a 21-item self-report measure in which the items are added to form a total score. In this sample, Cronbach’s alpha for the scale was .89.

Worry was assessed with the Worry Subscale of the Family Burden Interview Schedule – Short Form (57). The Worry subscale asks participants about seven dimensions of worry rated on a 5-point Likert scale and items are added to form a total score. Cronbach’s alpha for this scale was .71.
general. In addition, five items were added to assess use of strategies involving accessing community resources to deal with mental illness in a relative (e.g., attending a support group). The full coping measure used in this study included 53 items. Cronbach’s alpha for this measure was .84.

We divided the subscales of the COPE into adaptive coping and maladaptive coping, based on strategies previously reported to be associated with positive or negative outcomes, respectively. Adaptive coping subscales included active coping, use of instrumental and emotional social support, positive reinterpretation and growth, religious coping, humor, acceptance, and use of community resources (Cronbach’s alpha = .85). Maladaptive coping subscales included mental and behavioral disengagement, denial, substance use, focus on and venting of emotions, and self-blame (Cronbach’s alpha = .80). In this sample, adaptive and maladaptive subscales were not significantly correlated with each other ($r = .17, p > .05$).

**Attributions of illness symptoms and behaviors** were evaluated with a modified version of Russell’s Causal Dimension Scale (60). On this scale, relatives are asked to rate their causal beliefs about the client’s illness and behaviors related to the illness in terms of three factors: 1) controllability (i.e., how much control the client has over his or her symptoms), 2) responsibility (i.e., how much responsibility the client has for the illness and the individual symptoms), and 3) intentionality (i.e., the degree to which relatives perceive the client as having willfully brought on the illness or the symptoms). Scores are then added to form a total score, and range from 9 to 81 with higher scores indicating greater blame of the client. Cronbach’s alpha for this scale in the sample was .79.

**Criticisms and emotional over-involvement** were evaluated with the Five Minute Speech Sample (FMSS, (61). The FMSS is measure of expressed emotion that involves identifying emotions, feelings, and attitudes expressed by a respondent about a relative with mental illness during a five-minute monologue. Participants are interviewed individually and asked to speak for five minutes about the client while they are recorded by audiotape. The tapes are then coded for criticism and emotional over-involvement and are rated on a 3-point scale corresponding to high, borderline, or low in each of these categories. Respondents can then be classified as either high or low in expressed emotion based on these ratings. To allow maximum sensitivity to independently examine criticism and emotional involvement, we analyzed data using continuous 3-point scales for each category as described above. Previous research has shown that rating of these dimensions of expressed emotion on the FMSS are related to ratings based on the more extensive Camberwell Family Interview (61, 62).

**Results**

We first computed correlations to examine the relationships between hope and the different measures of distress (burden, worry, anxiety, and depression). These correlations are presented in Table 2. All of the measures of distress were significantly intercorrelated, with Pearson’s $r$’s ranging from .36-.63. Hope, on the other hand, was negatively correlated with worry and burden, but not depression and anxiety. Therefore, for subsequent analyses we combined the distress measures by standardizing the scores (i.e., computing $z$-scores) and summing them to form a composite measure of distress. Cronbach’s alpha for this composite was .81. The correlation between distress and hope was $r = -.38$ ($p < .01$).

We then examined the relationships between the different measures of relatives’ reactions to the mental illness (coping strategies, attributions, criticism, emotional overinvolvement). Only one significant correlation was found: relatives who reported using more adaptive coping strategies had less blame towards the client for their illness ($r = -.32, p < .05$).

**Demographic and illness-related characteristics**

We examined relationships among demographic characteristics of the participant (age, gender), demographic characteristics of the ill relative (age of the client, number of years since diagnosis, whether or not they were living with their affected relative), and participants’ hope and distress using $t$-tests (for categorical variables) and correlations (for continuous variables). Hope was not related
to any participant demographic or illness-related characteristics. Distress was negatively correlated with the age of the participant ($r = -.31, p = .03$) and with reports of how many years ago their relative was first diagnosed with schizophrenia or schizoaffective disorder ($r = -.30, p < .05$), but not any other characteristics. Older participants and those whose relatives had been ill for longer periods of time reported less distress.

When we examined relationships between demographic characteristics of the participant and client and participants’ reactions to their relative’s mental illness, only one correlation was statistically significant: women reported using more adaptive coping strategies than men, $t(45) = 2.65, p < .05$.

**Distress, hope and relatives’ reactions to mental illness**

Correlations between distress, hope and participants’ reactions to their relative’s mental illness, only one correlation was statistically significant: maladaptive coping was associated with greater distress and less hope.

We then used stepwise multiple regressions to examine the relationships between relatives’ reactions to the client’s illness and their levels of distress and hope, controlling for participant age and years since the relative’s diagnosis. Stepwise multiple regressions include only variables that significantly contribute to the model (entering the most strongly related variables first), after taking into account shared variability with the other predictors. Only maladaptive coping strategies entered the model, $F(1, 38) = 24.8, p < .001$, which explained 34.9% of the variance in distress. Similarly, maladaptive coping was the only predictor variable that entered the model in the stepwise multiple regression predicting hope, $F(1, 42) = 5.89, p < .05$, which accounted for 10.2% of the variance.

Because maladaptive coping was significantly related to both relatives’ distress and hope, we also conducted exploratory analyses examining the associations between the specific maladaptive COPE subscales and these outcomes. Pearson correlations between the maladaptive subscales of the COPE and distress revealed that more mental disengagement ($r = .58, p < .01$), behavioral disengagement ($r = .52, p < .01$), denial ($r = .51, p < .01$), self-blame ($r = .50, p < .01$), and focus on and venting of emotions ($r = .46, p < .05$) were all positively correlated with distress. With respect to hope, behavioral disengagement ($r = -.36, p < .05$) was the only significant predictor. Greater disengagement was associated with lower levels of hope.

In the stepwise multiple regression predicting distress and controlling for participant age and years since relative’s diagnosis, only mental disengagement entered the model, $F(1, 43) = 16.9, p < .001$.

### Table 2. Correlations among Hope and Measures of Relatives’ Distress

<table>
<thead>
<tr>
<th></th>
<th>Hope</th>
<th>Worry</th>
<th>Burden</th>
<th>Depression</th>
<th>Anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hope</td>
<td>Pearson Correlation</td>
<td>Sig. (2-tailed)</td>
<td>1</td>
<td>-.349*</td>
<td>-.373**</td>
</tr>
<tr>
<td>Worry</td>
<td>Pearson Correlation</td>
<td>Sig. (2-tailed)</td>
<td>-.349*</td>
<td>1</td>
<td>-.557**</td>
</tr>
<tr>
<td>Burden</td>
<td>Pearson Correlation</td>
<td>Sig. (2-tailed)</td>
<td>-.373**</td>
<td>-.557**</td>
<td>1</td>
</tr>
<tr>
<td>Depression</td>
<td>Pearson Correlation</td>
<td>Sig. (2-tailed)</td>
<td>-.157</td>
<td>-.364*</td>
<td>-.570**</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Pearson Correlation</td>
<td>Sig. (2-tailed)</td>
<td>-.244</td>
<td>-.456**</td>
<td>.535**</td>
</tr>
</tbody>
</table>

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).
<.001, \( R^2 \) change = .242. In the stepwise multiple regression predicting hope, only behavioral disengagement entered the model, \( F(1, 47) = 9.78, p < .01, R^2 \) change = .155).

To explore whether the same results would be found when the sample was restricted to all members from different families, the family member with the highest reported contact with the patient was retained in a subsample of 37 participants. The same basic pattern of associations was present in this subsample of participants. Maladaptive coping strategies continued to be highly correlated with distress (\( r = .60, p < .001 \)). Although the magnitude of the correlation between maladaptive coping and hope was almost identical in the restricted sample to that in the full sample (\( r = -.27 \) for restricted, \( r = -.30 \) for full) it was no longer statistically significant due to the smaller sample size (\( p = .13 \)).

**Table 3. Correlations of Hope and Distress with Reactions to Relatives’ Illness**

<table>
<thead>
<tr>
<th></th>
<th>Hope</th>
<th>Distress</th>
<th>Adaptive Coping</th>
<th>Maladaptive Coping</th>
<th>Criticism</th>
<th>Emotional Over-involvement</th>
<th>Blaming Attributions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hope</strong></td>
<td>Pearson Correlation</td>
<td>.379**</td>
<td>-.061</td>
<td>-.303*</td>
<td>-.244</td>
<td>-.005</td>
<td>.053</td>
</tr>
<tr>
<td>Sig. (2-tailed)</td>
<td>.007</td>
<td>.685</td>
<td>.035</td>
<td>.094</td>
<td>.973</td>
<td>.714</td>
<td></td>
</tr>
<tr>
<td><strong>Distress</strong></td>
<td>Pearson Correlation</td>
<td>-.379**</td>
<td>.080</td>
<td>.683**</td>
<td>.234</td>
<td>-.075</td>
<td>.081</td>
</tr>
<tr>
<td>Sig. (2-tailed)</td>
<td>.007</td>
<td>.600</td>
<td>.000</td>
<td>.117</td>
<td>.620</td>
<td>.581</td>
<td></td>
</tr>
<tr>
<td><strong>Adaptive Coping</strong></td>
<td>Pearson Correlation</td>
<td>-.061</td>
<td>1</td>
<td>.174</td>
<td>-.089</td>
<td>.228</td>
<td>-.322*</td>
</tr>
<tr>
<td>Sig. (2-tailed)</td>
<td>.685</td>
<td>.600</td>
<td>.248</td>
<td>.564</td>
<td>.136</td>
<td>.027</td>
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<tr>
<td><strong>Maladaptive Coping</strong></td>
<td>Pearson Correlation</td>
<td>-.303*</td>
<td>.683**</td>
<td>1</td>
<td>.127</td>
<td>.009</td>
<td>.006</td>
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<tr>
<td>Sig. (2-tailed)</td>
<td>.035</td>
<td>.000</td>
<td>.248</td>
<td>.397</td>
<td>.953</td>
<td>.967</td>
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<tr>
<td><strong>Criticism</strong></td>
<td>Pearson Correlation</td>
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<td>.234</td>
<td>-.089</td>
<td>.127</td>
<td>1</td>
<td>-.245</td>
</tr>
<tr>
<td>Sig. (2-tailed)</td>
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<td>.117</td>
<td>.564</td>
<td>.397</td>
<td>.904</td>
<td>.104</td>
<td>.238</td>
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<td>Sig. (2-tailed)</td>
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<td>.620</td>
<td>.136</td>
<td>.953</td>
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<td>.740</td>
<td>.049</td>
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<tr>
<td><strong>Blaming Attributions</strong></td>
<td>Pearson Correlation</td>
<td>.053</td>
<td>.081</td>
<td>-.322*</td>
<td>.006</td>
<td>.238</td>
<td>.049</td>
</tr>
<tr>
<td>Sig. (2-tailed)</td>
<td>.714</td>
<td>.581</td>
<td>.027</td>
<td>.967</td>
<td>.104</td>
<td>.740</td>
<td>1</td>
</tr>
</tbody>
</table>

**Correlation is significant at the 0.01 level (2-tailed).**

*Correlation is significant at the 0.05 level (2-tailed).*
Discussion

Findings from this study provide partial support for our hypotheses. Relatives who reported using more maladaptive coping strategies had higher levels of distress and less hope than those who used fewer such coping strategies. However, neither distress nor hope were related to relatives’ reported use of adaptive coping strategies, levels of criticism or overinvolvement, or their attitudes of blame for the illness on their family member. Hope and distress were only modestly correlated with each other, sharing about 15% of the variance.

The finding that maladaptive coping was correlated with distress is consistent with previous research showing that resignation and avoidance of a relative with schizophrenia is related to anxiety and depression (15) and worse emotional adjustment in relatives (16). Our analyses of the subscales of maladaptive coping found that mental disengagement (behaviors aimed at distracting a person from thinking about a stressor) was a primary predictor of distress in relatives.

Also consistent with our hypotheses, we found that maladaptive coping strategies were associated with less hope about the client’s future. In particular, we found that behavioral disengagement (reducing one’s effort to deal with a stressor) was the primary predictor for hope in relatives participating in this study. The relationship between maladaptive coping strategies and hope has not previously been studied in relatives of individuals with schizophrenia. However, Geffken and colleagues (47) found that hope in relatives of individuals with obsessive-compulsive disorder was negatively associated with denial/disengagement coping strategies.

Contrary to our prediction, we did not find that adaptive coping strategies were associated with hope or distress. That is, strategies such as seeking emotional and instrumental support, active coping, positive reinterpretation and growth, religion, humor, acceptance, and use of community supports were not associated with less burden or greater hope in relatives. This finding contrasts with the literature suggesting that adaptive coping strategies are predictive of less burden and distress for relatives (14, 15). The relationship between hope and adaptive coping strategies in relatives of individuals with schizophrenia had not previously been studied. However, our results differ from the findings reported by Geffken and colleagues (47) in obsessive-compulsive disorder. Geffken et al. reported that family members of individuals with obsessive-compulsive disorder who showed greater levels of hope were also more likely to use the adaptive coping strategies of active reframing and social support coping strategies.

Also contrary to our hypotheses, we did not find that criticism, emotional overinvolvement or blaming attributions were related to distress or hope in participants. The relationship between these factors and hope in relatives of individuals with schizophrenia had not previously been studied. Previous studies investigating the relationship between burden and expressed emotion have suggested that high expressed emotion is associated with greater burden of care, and that changes from high to low expressed emotion are associated with reduced burden over time (24, 25). One possible factor that may have influenced our sample is the relatively low rate of high expressed emotion in the sample. Only 6 of 51 participants were rated as high in criticism, and only 13 of 51 participants were rated as high in emotional overinvolvement. These low rates may reflect a limitation of the FMSS for assessing expressed emotion, since previous research has shown that it tends to under-detect high expressed emotion when compared to the “gold standard” of the Camberwell Family Interview (63, 64).

Older participants and those whose relatives had been ill for a longer period of time reported less distress. This suggests that relatives who had a longer time to adjust to living with the illness experience less distress over time, and that greater age may be a protective factor for dealing with the illness. Addington, McCleery and Addington (65) found that families of relatives participating in a first-episode psychosis program showed a reduction in distress over time. However, these families were offered family counseling and support as a part of the program. A factor that may have influenced the relationship between years since diagnosis and distress in this sample may be the clinical status of the ill relatives. That is, those relatives who had more time to adjust to the illness may have begun to recover and therefore their families may have
been less likely to be subjected to burdens related to crisis and hospitalization. It is also possible that more distressed family members over time become less involved and have less contact with their ill relative, and are thus less likely to participate in family psychoeducation at an older age.

Overall, these findings underscore the need for family interventions to reduce maladaptive coping strategies, particularly mental and behavioral avoidance strategies. Reliance of family members on mental and behavioral disengagement techniques may limit their ability to deal directly with the challenges of their relative's illness, to grieve losses associated with the illness, and to move on to develop new hope for the future of their loved one. This could have the effect of worsening distress and limiting hopefulness about the future. Therefore, effective family interventions should target these factors by helping relatives remain engaged with their relative and work through problems as they arise. It may also be especially important to teach families about recovery in order to foster a sense of hope for their relative.

This study had several limitations. The number of participants was small and only included people who were about to take part in a family psychoeducation program. Thus, this may reflect a group of individuals who are motivated to learn about dealing with schizophrenia, and therefore are predisposed to using adaptive coping strategies. Also, as an IRB regulation, all participants in the study were required to obtain permission to take part in the study from their ill relative. Therefore, some of the most distressed families (e.g., those whose relatives were missing, were too distrustful, or were preoccupied by symptoms) may not have been represented in this group.

Another limitation is that we did not assess clients’ clinical status as a part of this study. As reported by Perlack et al. (66), the severity of client symptoms is strongly related to family burden among family members of participants. Not being able to control for client symptom severity could have obscured relationships among the study variables. One additional consideration is that the results cannot speak to the direction of the associations between negative coping strategies, distress, and hope in families. That is, maladaptive coping strategies may lead to more distress and hopelessness in families or, alternatively, highly distressed and hopeless family members may be more likely to turn to avoidance and other maladaptive coping strategies. These associations may be bidirectional or cyclical, depending on the family, with different coping strategies contributing to increased or decreased distress, as well as distress leading to different types of coping. Regardless of the possible directions, family psychoeducation aimed at reducing avoidance and increasing hope for families may foster better coping, reduced distress, and increased hope.

References

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