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The relationship between the perceived risk of harm by a family member with mental illness and the family experience

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Abstract

Family members of people with serious mental illness (SMI) at times report that they act to stop their ill relative from self harm or harming others. This study examines the relationship between the perception of risk of harm and family distress, burden, empowerment, coping, physical and mental health, appraisal of the caregiving experience, family communication, and family functioning. The study is a secondary analysis of baseline data collected for a randomized study of the family-to-family peer driven education program (FTF). Four hundred thirty-four enrolled individuals who were seeking to participate in FTF completed survey items that asked if they had tried to stop or prevent their ill family member from harming themselves or others in the last 30 days. Participants who perceived a recent risk of harm by their ill relative reported more negative appraisals of caregiving, greater psychological distress, poorer mental health and greater objective burden compared with those who did not perceive a recent risk of harm. The results suggest that families of persons with SMI should be asked about perceived risk of harm to self and others, and the presence of perceived risk of harm should serve as a red flag indicating the need for further evaluation of the family experience and additional support for the family.

Keywords

Severe Mental Illness; Family; Distress; Burden; Harm; Violence; Suicide

Introduction

Families play an important role in the support network of persons with serious mental illness (SMI) (Dixon & Lehman, 1995; Gaite et al., 2002; Jones, Roth, & Jones, 1995). However, it is well established that mental illness can act as a stressor for family members (Lucksted, Stewart, & Forbes, 2008; Solomon & Draine, 1995; Szmukler et al., 1996). The concerns of relatives of those with mental illness are varied and include but are not limited to concerns about difficult behaviors, stigma, problems accessing treatment, effects on other family members, and the risk of suicide and physical harm to others (Fadden, Bebbington, &

Kuipers, 1987; Jungbauer, Wittmund, Dietrich, & Angermeyer, 2004; Kjellin & Ostman, 2005; Szmukler et al., 1996). Perceptions of risk of harm to self or others represent a potentially severe stress for family members. Previous efforts to understand the impact on families of perceived risk of harm to self or others have combined such perceptions with other symptomatic or disruptive behaviors. These aggregated experiences have consistently been associated with greater objective and subjective burden (Baronet, 1999; Pickett, Greenley, & Greenberg, 1995; Potasznik & Nelson, 1984; Provencher & Mueser, 1997; Schulze & Rossler, 2005). With the exception of the study by Pickett et al., previous studies have tended to be small with narrow samples (Pickett et al., 1995). The study of the association between symptoms/disruptive behaviors and caregiver burden and distress is also plagued by the use of many different measures for these constructs with varying psychometric properties (Kjellin & Ostman, 2005; Pickett et al., 1995; Potasznik & Nelson, 1984; Provencher & Mueser, 1997; Vaddadi, Gilleard, & Fryer, 2002). Overall, little is known about perceived risk of harm to self or others, distinct from other disruptive and symptomatic behaviors, and their relationship to family distress and burden.

The present study investigates the associations between perceived risk of harm, burden, distress and caregiver mental health within a stress coping model (Szmukler et al., 1996). In this model, perceived risk of harm and burden act as stressors, and distress and caregiver mental health are outcomes. Mediating factors within the stress coping model include appraisal of caregiving, emotion focused coping (the cognitive and behavioral efforts used to control the demands of the stressor), caregiver physical health, family functioning, and family communication (use of incendiary communication which tends to exacerbate stressful situations and affirming communication which conveys support, and caring and exerts a calming influence) (McCubbin, McCubbin, & Thompson, 1996). Family communication may be related to the construct of expressed emotion but the difference in the method of measurement (self report vs. direct observation) is likely to be important. The different components of the stress coping model are viewed as bidirectional or circular (Szmukler et al., 1996).

Knowledge regarding the relationship between family experience and *actual* violence by a relative with SMI is sparse. Kjellin & Ostman (2005) investigated the influence of *documented* violence on family burden and family mental health problems among family members of recently admitted psychiatric inpatients in Sweden (N=155). No differences in family burden and family mental health problems were observed between relatives of patients with and without a documented history of violence against others. Relatives of patients with documented suicide attempts in the preceding month were more likely to report interference in their social life, mental health problems of their own and a personal need for psychiatric services compared with relatives of patients without a documented recent history of suicide. They were also more likely to report being worried about suicide attempts by the patient (Kjellin & Ostman, 2005). However, this study does not address how perceived risk of harm rather than actual experience of violence affects families. To our knowledge, there is no literature directly addressing this issue (Baronet, 1999; Schulze & Rossler, 2005).

Understanding the impact of perceived risk of harm may be important because such worries are likely to be far more common than actual violence. These worries may be exacerbated

by media focus on violence and its distorted associations with mental illness (Corrigan et al., 2005; Corrigan, Powell, & Michaels, 2013; NAMI, December 20, 2012). Perceived risk of harm may be associated with increased family distress and burden which may diminish or alter the support that family members can provide to their loved ones. Greater understanding of how and under what circumstances families perceive risk may help to mitigate actual risk by informing the psychoeducation provided to families and consumers regarding how to navigate such stressful situations. For example, family members might benefit from strategies to remove access to weapons in order to keep themselves and their loved ones safe. In addition, family members might benefit from learning about how to identify risk factors or warning signs and when to contact mental health professionals vs. law enforcement.

Using data collected for a randomized study of the family-to-family peer driven education program (FTF) conducted in Maryland, this study investigates whether FTF participants' perceptions that they had to take action to stop or prevent their ill relative from harming self or others is associated with a range of family members' experiences. The term "perceived risk of harm" is used throughout the manuscript to concisely describe the perception of trying to stop or prevent the ill relative from harming self or others. We hypothesized that perceived recent risk of harm to self and/or others would be associated with greater family distress, burden, negative appraisal of care giving, incendiary communication within the family as well as lower levels of family functioning, empowerment, positive appraisal of care giving, and affirming communication within the family.

Methods

Procedures and Participants

As previously described (Dixon et al., 2011; Marcus et al., 2013), the FTF program is a 12-week program offered by the National Alliance on Mental Illness (NAMI) and taught by trained family-member volunteers (Dixon et al., 2011; Marcus et al., 2013). This study included two participant groups. The term "participant" is used here to refer to the family member enrolled in the FTF class. The first participant group consisted of individuals who participated in a randomized controlled trial (RCT) examining the efficacy of FTF on family member outcomes (Dixon et al., 2011). The second group consisted of individuals who declined randomization in the RCT but who were planning to take the class and who consented to be a part of a nonrandomized arm (Marcus et al., 2013). Both cohorts were recruited from five Maryland NAMI affiliates: Baltimore Metropolitan region and Howard, Frederick, Montgomery, and Prince George's counties. Consenting participants were assessed at baseline (before FTF started) with a structured telephone interview that lasted approximately 60 minutes. Participants were recruited between March 15, 2006, and September 23, 2009, and were enrolled in 54 different classes. They were paid \$15 for each interview. A total of 438 individuals completed the baseline interview. One individual in the control group was found to have taken the FTF course and was removed from the analysis. Three individuals were excluded due to missing data for the variables used to define the risk-of-harm groups. The remaining 434 individuals included 61 pairs of parents who participated in the study. Data from each parent were included in the analysis as each parent

may perceive risk of harm and experience distress differently. The current study uses only the baseline interview. (See Dixon et al. (2011) and Marcus et al. (2013) for a more detailed description of the recruitment process, randomized sample and nonrandomized sample.)

This study was approved by the University of Maryland Institutional Review Board. All authors certify responsibility for the manuscript and the authors have no known conflicts of interest.

Assessments and variables

Baseline assessments focused on demographics of both the participant and ill relative for whom the participant took the course, psychiatric history of the ill relative, subjective illness burden in the participant, objective illness burden in the participant, empowerment in the participant, the participant's appraisal of the caregiver experience, emotion-focused coping of the participant, psychological distress of the participant, physical and mental health of the participant, family communication and family functioning. Cronbach's alphas were calculated for all measures as used in this sample. Cronbach's alpha was greater than 0.80 for all measures except the ECI negative subscale (Cronbach's alpha = 0.79).

Demographics and background—The Family Experiences Interview Schedule (FEIS) was used to obtain background information (Tessler & Gamache, 1993). The instrument elicits information about participant demographic characteristics, level of involvement with the participant's ill relative, and the ill relative's demographic characteristics and psychiatric history.

Perceived risk of harm—Perceived recent risk of harm was defined as a response of “YES” to the following statements in the FEIS from the baseline interview: “In the past 30 days, did you try to prevent or stop (ill relative's name) from injuring or threatening to injure anyone?” (Harm to Others) and/or “In the past 30 days, did you try to prevent or stop (ill relative's name) from talking about, threatening, or attempting suicide?” (Harm to Self).

Subjective and objective illness burden—The FEIS worry and displeasure scales measure subjective illness burden. The eight-item worry subscale asks participants to rate their level of concern on different aspects of their ill relative's life. Two items referring to worry about physical health and safety were removed from the FEIS worry scale for this analysis to prevent a spurious association with the perceived risk of harm groups. The eight-item displeasure subscale measures the participant's emotional distress concerning the ill relative's situation. The worry and displeasure subscales have been found to be internally consistent, with Cronbach's alphas of 0.89 and 0.85, respectively (Tessler & Gamache, 1993). These psychometric properties represent those for the full subscales and do not account for the items removed for this study.

The FEIS objective assistance in daily living and objective supervision subscales measure objective burden by asking the participant “During the past 30 days, how often did you help with (various activities of daily living)?” and “During the past 30 days, how often did you try to prevent or stop (various disruptive or troubling behaviors)?”, respectively. The two items used to define the perceived recent risk of harm groups were removed from the

supervision subscale. The objective assistance in daily living and objective supervision subscales have Cronbach's alphas of 0.78 and 0.65, respectively (Tessler & Gamache, 1993). These psychometric properties represent those for the full subscales and do not account for the items removed for this study.

Empowerment—The Family Empowerment Scale (FES) measures empowerment defined by Staples as “...the ongoing capacity of individuals or groups to act on their own behalf to achieve a greater measure of control over their lives and destinies (Koren, DeChillo, & Friesen, 1992).” It has three subscales: family (12 items), community (10 items), and service system empowerment (12 items). The FES has been validated with a sample of parents of children with emotional, behavioral or mental disorders, in which the three subscales were found to be internally consistent, with Cronbach's alphas of 0.87-0.88 (Koren et al., 1992). The scale was adapted for use in care providers of adults with mental illness for previous studies of FTF efficacy. In those studies FES scores increased significantly after participation in FTF which supports the scale's validity in this population (Dixon et al., 2001; Dixon et al., 2004; Dixon et al., 2011).

Emotion-focused coping—The Coping Inventory (COPE) measures emotion focused coping using five subscales: emotional social support, positive reinterpretation, acceptance, denial, and turning to religion. The COPE has demonstrated good reliability and validity and has been adapted for family members of individuals with serious mental illness (Carver, Scheier, & Weintraub, 1989).

Psychological distress—The Brief Symptom Inventory (BSI-18) and the Center for Epidemiological Studies Depression Scale (CES-D) measure distress (Derogatis, 2001; Radloff, 1977; Radloff & Lock, 1986). The BSI-18 is a measure of psychological distress designed for use primarily in nonclinical, community populations. It measures level of somatization, anxiety, and depression and generates a total score of the respondent's overall level of distress (Global Severity Index (GSI)). The BSI-18 has well-established reliability and validity (Derogatis, 2001). The modified version of the CES-D is a reliable and valid 14-item scale designed to measure depressive symptoms in the general population (Radloff, 1977; Radloff & Lock, 1986). Higher scores on the CES-D and BSI-18 indicate greater distress.

Physical and mental health—The SF-12 is a reliable and well validated measure of health and yields scores for physical and mental health (Ware, Kosinski, & Keller, 1996) (accessed 9/9/13 <http://www.sf-36.org/tools/sf12.shtml>). Higher scores on the SF-12 indicate better health.

Family functioning—The Family Assessment Device (FAD) evaluates family functioning and family relations and is used in studies of family response to illness (Epstein et al., 1983; McCubbin et al., 1996). Example items include “In times of crisis we can turn to each other for support” and “There are lots of bad feelings in the family.” It has well established reliability and validity. We used the general functioning (12 items) and problem-solving (five items) subscales.

Family communication—The ten-item Family Problem Solving Communication (FPSC) index measures positive and negative aspects of communication within the family (eg. “We work to be calm and talk things through” and “We yell and scream at each other,” respectively) (McCubbin et al., 1996).

Appraisal of the caregiving experience—The Experience of Caregiving Inventory (ECI) assesses the appraisal of the caregiving experience (Szmukler et al., 1996). The ECI is a self-report measure that includes ten subscales, eight negative (difficult behaviors; negative symptoms; stigma; problems with services; effects on family; need to backup the ill relative; dependency; and loss), and two positive (rewarding personal experiences; and good aspects of relationship with the patient). The negative score is a sum of all the negative subscales and the positive score is a sum of both positive subscales. Regarding each item, the caregiver is asked “during the last month, how often have you thought about...” Of note, the loss subscale includes three items referring to self-harm. These items were removed from the loss subscale score for this analysis to prevent a spurious association with the perceived risk of harm groups. These items were also removed for the negative score. No subscale directly addresses risk for harming others.

Data analysis

The baseline data generated four groups. Participants in the first group endorsed both the Harm to Self item of the FEIS and the Harm to Other item (BOTH). The second and third groups endorsed only the Harm to Self item (SELF) and Harm to Other (OTHER) item, respectively. The final group endorsed neither item (NONE). A oneway analysis of variance (ANOVA; SAS PROC GLM) with post hoc comparisons to control for multiple contrasts within each ANOVA was used to assess differences between the BOTH, SELF, OTHER groups and the comparison group (NONE) for continuous variables. A chi-square (Wald X^2 ; PROC Logistic) was used to assess differences between BOTH, SELF, OTHER groups and the comparison group (NONE) for dichotomous variables. The DUNNETT method was used to adjust for multiple contrasts. No correction was made for assessing multiple outcomes.

Results

Participants

One hundred and four individuals (24%) responded yes to “In the past 30 days, did you try to prevent or stop (ill relative's name) from injuring or threatening to injure anyone?” AND/OR “In the past 30 days, did you try to prevent or stop (ill relative's name) from talking about, threatening, or attempting suicide?” Of those responding “yes” to those items, 28 (26.7%; 6.5% of the total sample) responded “yes” only to self harm, 48 (45.7%; 11% of the total sample) responded “yes” only to harming others, and 28 (26.7%; 6.5% of the total sample) responded “yes” to both items.

Table 1 shows the descriptive characteristics of those with perceived recent risk of harm to self (SELF), perceived recent risk of harm to others (OTHERS), perceived recent risk of harm to self and others (BOTH) and those *without* perceived recent risk of harm (NONE).

FTF participants in all three harm groups were more likely to report that their ill family member had a hospitalization for mental health reasons in the previous 6 months and had a greater number of hospitalizations in the previous 6 months than those without a perceived recent risk of harm. The ill family members of participants in the OTHERS and BOTH groups were younger, and received their first mental health help at a younger age than the NONE group. The ill relatives with perceived recent risk of harm to others (OTHERS) were less likely to be living independently compared with the ill relatives in the NONE group.

Comparisons of Family Experiences by Group (See Table 2)

Subjective and Objective Illness Burden—Subjective burden was significantly greater in the BOTH and OTHERS groups compared with the NONE group as measured by the FEIS worry and displeasure scales. All perceived recent risk of harm groups (SELF, OTHERS, and BOTH) reported greater objective burden compared with the NONE group as measured by the FEIS daily living assistance and supervision subscales. The FTF participants in the OTHERS and BOTH groups were more likely to report that they tried to prevent their ill relative from drinking too much and using drugs in the past 30 days compared with the FTF participants in the NONE group.

Empowerment—Empowerment in the domains of family and community was generally comparable across groups. However, in the domain of the service system, individuals in the OTHERS group had significantly greater empowerment than those with no perceived risk.

Emotion-focused coping—Participants who reported trying to stop or prevent their ill relative from hurting others (OTHERS) endorsed greater use of religious coping compared with the NONE group. No other differences were observed across groups in coping.

Psychological distress and physical and mental health—Psychological distress was greater in all perceived risk of harm groups (OTHERS, SELF, and BOTH) compared with the NONE group as measured by the CESD, the BSI, and the SF12 mental health scale. No differences were observed across groups in physical health.

Family functioning—Family functioning in general and family functioning in the domain of problem solving were comparable across groups.

Family communication—Participants reporting perceived risk to others (OTHERS) had significantly less use of affirming communication and greater use of incendiary communication than those with no perceived risk (NONE).

Appraisal of the caregiving experience

Negative aspects of the caregiving experience—All perceived risk of harm groups (OTHERS, SELF, and BOTH) had more overall negative appraisal of the caregiving experience compared with the NONE group. Table 2 shows the specific subscales.

Positive aspects of the caregiving experience—The only difference in these comparisons was that participants in the SELF group thought more often about the good

aspects of their relationship with the ill relative compared with participants in the NONE group.

Discussion

This study underlines the extent to which help-seeking family members of individuals with mental illnesses struggle with the core issue of the safety of their ill relative. Almost one quarter of a large sample of family members seeking to enroll in NAMI's FTF education program reported that they took some action to prevent their ill relative from harming themselves or others in the last 30 days. While caution must be exercised in interpreting this finding because the actual level of risk is unknown, it is clear that a substantial subset of FTF participants worry about harm. This underscores the importance of self-help programs like NAMI's FTF program in providing critical assistance and support to family members.

The associations between perceived risk of harm and family distress, burden and negative appraisal of caregiving suggest that when a relative reports a perceived risk of harm it should serve as a red flag to mental health providers indicating the need for further evaluation of the family experience. The results suggest particular areas of the family experience that should be probed. Participants enrolled in FTF reported significantly more negative appraisals of caregiving, regardless of whether the FTF participant reported preventing harm to self, others or both. The consistency of the associations of overall negative appraisal and most subtypes of negative appraisal with perceived risk of harm is dramatic and demands attention. The relatives who perceived a risk of harm had more frequent negative appraisals in the challenging domains of difficult behaviors, effects on the family, problems with services, stigma, dependency, and need to backup the ill relative. These findings illustrate the needs of family members who are struggling to be supportive of their ill relative. Relatives' negative appraisal of caregiving has been found to be a strong predictor of distress and was actually the only independent predictor of distress in an analysis that included demographic, social, and clinical characteristics (Harvey, Burns, Fahy, Manley, & Tattan, 2001). Relatives' negative appraisals have also been found to be positively associated with family burden (Ostman & Hansson, 2004).

Other areas of the family experience that should be probed upon learning of a relative's concern for harm include burden, and the relative's own mental health. Relatives who perceived a risk of harm against self, others, or both, had greater levels of objective burden, psychological distress and poorer mental health. Relatives who perceived a risk of harm against others, or both self and others, had greater levels of subjective burden compared to those who did not perceive a risk of harm. These findings are consistent with a previously reported association between a measure of burden, which included aggressiveness as a source of burden, and poorer caregiver mental health (Madianos et al., 2004). Furthermore, the current findings extend what is already known about the positive association between actual abuse of a caregiver, a form of documented harm to others, and emotional distress and burden (Vaddadi et al., 2002) and the positive association between documented violence against self and caregiver burden (Kjellin & Ostman, 2005). The current study therefore extends what was previously known by showing that perceived risk of violence is itself associated with increased family burden and distress. In clinical practice, it is at times

difficult to know whether actual violence has occurred or if the relative is accurately interpreting the risk of harm. The current findings suggest that even without information on actual violence or true risk of harm, the family's concern regarding harm is enough to indicate that the family is at greater risk for burden and distress and may require additional support.

The finding of an association between perceived risk of harm to others and increased distress, burden and negative appraisal, conflicts with a previous finding of no relationship between burden and documented violence against others (Kjellin & Ostman, 2005). The current findings suggest that perceived risk of harm to others and perceived risk of harm to self are more similar than different in relation to the distress and burden of the family. In light of the current findings, the previous finding of no relationship between documented violence against others and family burden may have been due to the methods of the study. In that study, the *recent* burden levels (1 month prior) of family members of those with documented *lifetime* violence against others were compared with relatives of those without *lifetime* violence. Thus the time frames for the stressor and hypothesized response (burden) were different. In contrast, the same study found that the families' burden levels in the previous month were positively associated with documented suicide attempts in the previous month. The sample used by Kjellin and Ostman also differed from that used in the current study. Kjellin and Ostman used a sample of relatives of psychiatric inpatients whereas the present study was conducted in a sample of self-help seeking relatives.

While the experience of relatives of those with a perceived risk of harm to *others* was similar to the experience of relatives of those with a perceived risk of harm to *self*, there were a few intriguing differences. Relatives who perceived a risk of harm to *others* used more religious coping, more incendiary communication and less affirming communication than relatives who did not perceive a risk of harm. The greater use of incendiary communication and lesser use of affirming communication in only the group of relatives with perceived risk of harm to *others* indicate that families with concern about harm to *others* should be asked about communication in the household. A causal relationship cannot be established based on our analysis. If there is a causal relationship between communication type and perceived risk of harm to others, it is plausible that the relationship is bidirectional and interventions focused on improving communication may reduce perceived aggressive behavior which would further reduce incendiary communication and increase affirming communication. Greater religious coping was found only in the group of relatives who perceived a risk of harm to others. The meaning of this finding in the context of there being no other coping differences remains unclear and requires replication.

Those relatives who perceived a risk of harm to *self* also had a unique finding. More frequent thoughts about the good aspects of the relationship were seen only in the relatives who perceived a risk of harm to self. This could be a response to fear of loss.

This study has several limitations. The results reported here are correlations and causation cannot be assumed. The analysis is limited by a lack of information about the ill relative including diagnoses and severity of illness. In addition, the sample does not represent all families of those with SMI because the sample was drawn from a select population of

families interested in participation in the FTF program. These families were motivated to seek out help from a self-help program. The prevalence of perceived risk of harm in this sample is likely greater than that which would be found in a sample of non-self-help seeking families because the perceived risk of harm may motivate self-help seeking. Furthermore the sample was drawn from only one geographic area. The sample sizes of some of the risk groups (those who perceived harm to self and those who perceived harm to both self and others) were small and therefore the contrasts may have been underpowered to find differences compared to the group with a larger sample (those who perceived harm to others). The comparisons that failed to reach significance in those groups therefore require replication in a larger study. Replication is also required due to the exploratory post hoc nature of the analysis.

While the use of many well validated measures is a strength of this study, the harm groups were defined by single items that have not been previously used for this purpose. Perceived risk of harm was operationalized as self report of trying to prevent or stop the ill relative from injuring or threatening to injure anyone and/or talking about, threatening, or attempting suicide. This measure is difficult to validate as we cannot verify that individuals actually took action to prevent or stop harm. It is also possible that there were individuals who perceived a risk of harm but did not act to prevent or stop it. Those individuals would be misclassified as not perceiving risk of harm. This type of misclassification would have reduced the power to identify significant associations, and thus introduces a conservative bias.

It is also important to note that perceived risk of harm is a component of objective burden but was removed from the objective burden measure for analysis to prevent the finding of a spurious association. The items of the objective burden scale are known to be correlated. It is therefore possible that perceived risk of harm represents a surrogate for overall objective burden.

In conclusion, a significant minority of family members pursuing participation in the NAMI FTF program perceived that they attempted to stop threats of harm or actual harm to others, self, or both by their ill family member in the preceding month. Perceived recent risk of harm is associated with more negative appraisals of caregiving, greater psychological distress, and greater burden. Mental health professionals are trained to inquire about perceived risk of harm in their assessment of actual risk of harm but the present findings highlight the importance of perceived risk of harm regardless of its relationship to actual risk. Perceived risk of harm is important when present and may be an indication that family members are in need of increased support.

In order to provide optimal support for families concerned about a risk of harm, additional research is needed on how families respond to perceived risk of harm, who they contact (law enforcement, primary psychiatrists, primary care providers, emergency departments), the outcomes of those contacts, and family satisfaction with the response of health professionals and law enforcement. This is an area that would greatly benefit from qualitative research. Qualitative research that provides a fuller understanding of perceived harm by family members could provide a foundation upon which to develop more sophisticated quantitative

measures of this experience. In addition, care can only be improved if there is an understanding of the care currently being provided. More needs to be known about whether mental health providers are discussing with families what they should do if they perceive a risk of harm and whether this reduces the burden and distress experienced by these families. The FTF curriculum addresses concern for suicide and violence by teaching participants to know the signs of impending violence and suicide, to take threats seriously, to follow their instincts, and to call for help. Participants are provided with contact information for community resources including crisis lines, mobile crisis units, and local hospitals. Families also learn to use communication skills and limit setting to help prevent violence (B. Stewart, personal communication, February 14, 2014). FTF has been shown to reduce participant distress in a randomized clinical trial (Dixon et al., 2011).

Based upon the findings presented here, clinicians should evaluate the level of burden and distress experienced by relatives who perceive a risk of harm and provide additional support to these relatives. The optimal form of support and intervention is unclear but a discussion of when to contact a helpline, the clinician, emergency department, and law enforcement is appropriate. The relatives may also benefit from a referral to a support group or educational program like FTF. The findings suggest that perceived risk of harm affects a large minority of those participating in family support programs and these programs should directly address this issue.

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Table 1

Descriptive characteristics

| | Risk Groups | | | | | | | | | | | |
|---|-----------------|---------|--|----------------------------------|---------|---------------------|------------------------------------|--------|---------------------|--|---------|---------------------|
| | No Risk (N=330) | | | Risk of Harming Self Only (N=28) | | | Risk of Harming Others Only (N=48) | | | Risk of Harming Self and Others (N=28) | | |
| | M(SD) | n(%) | | M(SD) | n(%) | Vs. No Risk (Adj p) | M(SD) | n(%) | Vs. No Risk (Adj p) | M(SD) | n(%) | Vs. No Risk (Adj p) |
| FTP Participant | | | | | | | | | | | | |
| Age | 52.9(11.1) | | | 49.8(9.5) | | .362 | 49.2(9.9) | | .067 | 50.2(6.7) | | .481 |
| Male | | 80(24) | | | 8(29) | .940 | | 10(21) | .938 | | 6(21) | .982 |
| White | | 223(68) | | | 22(79) | .577 | | 28(60) | .582 | | 18(64) | .969 |
| Completed 12+ yrs | | 323(98) | | | 28(100) | 1.000 | | 46(96) | .778 | | 28(100) | 1.000 |
| Income >\$50,000 | | 228(71) | | | 23(85) | .351 | | 27(57) | .151 | | 21(75) | .970 |
| Work full time | | 193(58) | | | 17(61) | .994 | | 26(54) | .921 | | 18(64) | .908 |
| Very involved with consumer | | 245(74) | | | 27(96) | .085 | | 41(85) | .265 | | 27(96) | .085 |
| Consumer | | | | | | | | | | | | |
| Age | 34.5(14.5) | | | 30.8(15.1) | | .463 | 23.7(11.3) | | <.001* | 27.1(13.3) | | .025* |
| Male | | 182(55) | | | 14(50) | .935 | | 26(54) | .999 | | 18(64) | .727 |
| Completed 12+ yr edu | | 290(88) | | | 23(82) | .730 | | 27(56) | <.001* | | 21(75) | .148 |
| Lives independently | | 112(34) | | | 8(29) | .908 | | 6(13) | .013* | | 6(21) | .440 |
| Married or living with partner | | 60(18) | | | 9(32) | .222 | | 3(6) | .137 | | 5(18) | 1.00 |
| Age received first mental health help | 22.0(12.6) | | | 20.8(13.3) | | .943 | 14.3(9.1) | | <.001* | 15.8(11.8) | | .040* |
| Length of illness | 11.9(11.0) | | | 10.1(10.0) | | .753 | 8.7(8.1) | | .137 | 10.0(8.3) | | .751 |
| Has a primary therapist etc. | | 230(71) | | | 24(86) | .263 | | 32(67) | .927 | | 20(71) | 1.00 |
| Ever hospitalized for mental health reason | | 237(72) | | | 20(71) | 1.00 | | 39(81) | .433 | | 27(96) | .063 |
| # Lifetimes hospitalizations | 2.4(3.9) | | | 4.2(11.2) | | .230 | 3.3(3.8) | | .638 | 5.0(9.3) | | .041* |
| Any mental health hospitalization in past 6 months | | 102(31) | | | 17(61) | .007* | | 25(52) | .015* | | 18(64) | .002* |
| # Hospitalizations in past 6 months for mental health | 0.4(0.7) | | | 1.3(1.8) | | <.001* | 0.8(1.1) | | .014* | 1.1(1.1) | | <.001* |

| | Risk Groups | | | | | | | | | | | |
|--|-----------------|--------|---------------------|----------------------------------|------|---------------------|------------------------------------|--------|---------------------|--|--------|---------------------|
| | No Risk (N=330) | | | Risk of Harming Self Only (N=28) | | | Risk of Harming Others Only (N=48) | | | Risk of Harming Self and Others (N=28) | | |
| | M(SD) | n(%) | Vs. No Risk (Adj p) | M(SD) | n(%) | Vs. No Risk (Adj p) | M(SD) | n(%) | Vs. No Risk (Adj p) | M(SD) | n(%) | Vs. No Risk (Adj p) |
| Homeless in past year | | 26(8) | .998 | | 2(7) | | | 9(19) | .057 | | 5(18) | .226 |
| Objective burden: Supervision | | | | | | | | | | | | |
| Family intervened due to ETOH in past 30 days | | 44(13) | .727 | | 2(7) | | | 14(29) | .018* | | 9(33) | .022* |
| Family intervened due to drugs in past 30 days | | 26(8) | 1.00 | | 2(7) | | | 13(27) | <.001* | | 12(43) | <.001* |

* p .05

Table 2

Relationship between perceived risk of harm and family experiences

| | | Risk Groups | | | | | | | | |
|---|-------------------|------------------------|--------------|---|--------------|---|--------------|---|--------------|----------------------------|
| | | No Risk (N=330) | | Risk of Harming Self Only (N=28) | | Risk of Harming Others Only (N=48) | | Risk of Harming Self and Others (N=28) | | |
| | | M(SD) | M(SD) | Vs. No Risk (Adj p) | M(SD) | Vs. No Risk (Adj p) | M(SD) | Vs. No Risk (Adj p) | M(SD) | Vs. No Risk (Adj p) |
| Appraisal of the caregiving experience | | | | | | | | | | |
| ECI Negative Appraisal Subscales | | | | | | | | | | |
| ECI Difficult behavior scale | 15.2(6.3) | 19.0(5.7) | .006* | 21.2(5.7) | <.001* | 21.5(6.2) | <.001* | | | |
| ECI Negative symptom scale | 13.3(4.9) | 14.9(4.4) | .277 | 16.3(4.7) | <.001* | 17.6(5.2) | <.001* | | | |
| ECI Stigma scale | 5.9(3.9) | 8.0(4.1) | .026* | 7.3(4.1) | .074 | 9.1(5.2) | <.001* | | | |
| ECI Problem with services scale | 13.5(6.8) | 17.6(6.7) | .006* | 15.9(6.7) | .065 | 19.5(6.7) | <.001* | | | |
| ECI Effect on family scale | 11.1(5.6) | 14.6(5.5) | .004* | 14.8(4.9) | <.001* | 16.1(6.3) | <.001* | | | |
| ECI Need to backup scale | 11.5(5.0) | 13.3(4.4) | .163 | 13.6(3.8) | .013* | 15.5(4.5) | <.001* | | | |
| ECI Dependency scale | 10.0(4.0) | 12.9(3.6) | <.001* | 12.2(3.4) | <.001* | 14.7(3.3) | <.001* | | | |
| ECI Loss scale | 8.3 (3.1) | 10.3(3.7) | .003* | 9.0(2.8) | .424 | 10.3(3.5) | .004* | | | |
| ECI Negative | 88.3(27.8) | 110.7(26.2) | <.001* | 110.2(19.3) | <.001* | 124.3(29.5) | <.001* | | | |
| ECI Positive Appraisal Subscales | | | | | | | | | | |
| ECI Positive personal experience | 17.1(5.7) | 18.9(5.6) | .285 | 18.6(5.2) | .236 | 18.7(5.5) | .376 | | | |
| ECI Good aspect of relationship | 13.0(4.1) | 15.0(4.5) | .049* | 12.5(4.8) | .813 | 12.9(3.9) | .999 | | | |
| ECI Positive | 30.1(8.3) | 33.8(8.9) | .066 | 31.0(8.0) | .830 | 31.6(8.2) | .734 | | | |
| Emotion focused coping | | | | | | | | | | |
| COPE Positive scale | 11.6(3.0) | 12.1(3.0) | .713 | 12.5(2.6) | .111 | 12.0(2.8) | .825 | | | |
| COPE Denial scale | 5.0(1.6) | 5.4(2.2) | .524 | 5.1(2.1) | .926 | 5.2(1.8) | .910 | | | |
| COPE Religious scale | 11.2(4.6) | 12.4(4.2) | .474 | 13.0(4.0) | .041* | 11.6(5.0) | .974 | | | |
| COPE Emotional scale | 12.0(3.3) | 12.4(3.6) | .883 | 11.9(3.4) | .995 | 11.9(3.1) | .994 | | | |
| COPE Acceptance scale | 12.6(2.4) | 12.9(1.7) | .919 | 13.0(2.5) | .621 | 12.6(2.5) | 1.00 | | | |

| | Risk Groups | | | | | | | |
|-------------------------------|-----------------|---------------------|---|---------------------|---|---------------------|---|---------------------|
| | No Risk (N=330) | | Risk of Harming Self Only (N=28) (SELF) | | Risk of Harming Others Only (N=48) (OTHERS) | | Risk of Harming Self and Others (N=28) (BOTH) | |
| | M(SD) | Vs. No Risk (Adj p) | M(SD) | Vs. No Risk (Adj p) | M(SD) | Vs. No Risk (Adj p) | M(SD) | Vs. No Risk (Adj p) |
| Empowerment | | | | | | | | |
| FES family scale | 3.4(0.6) | .973 | 3.4(0.6) | .999 | 3.4(0.7) | .994 | 3.4(0.7) | .994 |
| FES service system scale | 3.0(0.9) | .227 | 3.3(0.8) | .003* | 3.4(0.7) | .062 | 3.4(0.7) | .062 |
| FES community scale | 2.4(0.8) | .613 | 2.6(0.7) | .726 | 2.6(0.8) | .299 | 2.6(0.8) | .299 |
| Subjective burden | | | | | | | | |
| FEIS worry scale | 2.4(0.8) | .058 | 2.8(0.8) | .003* | 3.1(0.9) | <.001* | 3.1(0.9) | <.001* |
| FEIS displeasure scale | 2.7(0.8) | .315 | 3.0(1.0) | .008* | 3.2(1.0) | .023* | 3.2(1.0) | .023* |
| Psychological distress | | | | | | | | |
| CESD | 8.3(7.3) | .012* | 12.7(9.6) | .038* | 11.9(7.7) | .044* | 11.9(7.7) | .044* |
| BSI-GSI | 50.8(9.4) | <.001* | 57.6(9.4) | .012* | 55.8(10.6) | .023* | 55.8(10.6) | .023* |
| Family functioning | | | | | | | | |
| FAD general functioning scale | 2.1(0.5) | .706 | 2.2(0.5) | .576 | 2.2(0.7) | .802 | 2.2(0.7) | .802 |
| FAD problem solving scale | 2.2(0.5) | .963 | 2.2(0.4) | .562 | 2.2(0.6) | 1.00 | 2.2(0.6) | 1.00 |
| Family communication | | | | | | | | |
| FPSC affirming communication | 10.9(2.7) | .989 | 11.0(2.0) | .029* | 10.3(3.4) | .598 | 10.3(3.4) | .598 |
| FPSC incendiary communication | 5.5(3.1) | .286 | 6.5(2.6) | <.001* | 6.0(3.5) | .733 | 6.0(3.5) | .733 |
| Objective burden | | | | | | | | |
| Daily living assistance | 1.0(0.9) | .001* | 1.6(0.9) | <.001* | 2.1(0.9) | <.001* | 2.1(0.9) | <.001* |
| Supervision | 0.3(0.5) | .018* | 0.7(0.7) | <.001* | 1.4(0.8) | <.001* | 1.4(0.8) | <.001* |
| Health | | | | | | | | |
| SF12 Physical scale | 51.5(9.4) | .323 | 48.5(13.8) | .838 | 54.9(9.2) | .237 | 54.9(9.2) | .237 |
| SF12 Mental health | 46.0(10.8) | .010* | 39.5(11.8) | .013* | 37.3(11.2) | <.001* | 37.3(11.2) | <.001* |

* p .05