Factors Associated With the Emotional Distress of Women Family Members of Adults With Serious Mental Illness

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ABSTRACT

Women family members of adults with serious mental illness are at great risk for emotional distress. This study examined associations between characteristics of 60 women (age, race, and education), their relatives with mental illness (age, diagnosis, and years since diagnosis), and the family situation (relationship, living arrangements, and care provided) and symptoms of emotional distress. Depressive symptoms were greater among those with younger, non-sibling relatives. Anxiety was greater among Caucasians and those with a recently diagnosed family member, particularly bipolar disorder. Anger was associated with providing direct care. The findings are informative for tailoring interventions to minimize emotional distress in future family caregivers.

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Each year, more than 22% of the U.S. population are affected by a mental disorder considered serious, including schizophrenia, bipolar disorder, major depression, and anxiety (Jonas et al., 2012). Current estimates of specific categories of mental disorders indicate that approximately 2.4 million adults have schizophrenia, 5.7 million have bipolar disorder, 14.8 million have major depression, and 40 million have an anxiety disorder, which may include panic disorder, post-traumatic stress disorder, obsessive–compulsive disorder, generalized anxiety disorder or phobias (NIMH, 2008). The costs of these disorders to the nation are believed to exceed $300 billion annually, including expenditures for health care, lost wages, and disability benefits (Insel, 2008).

One in four families has at least one member with a mental disorder and family members often become their primary caregivers (World Health Organization, 2013). As a result, a large percentage of adults with serious mental illness are able to live in the community rather than being institutionalized. Over 75% of persons with serious mental illness who are discharged from treatment return, and up to 90% of those not living in the same household with other family members remain in close contact (Shankar & Muthuswamy, 2007). Thus, many of those with serious mental illness are receiving some type of support, assistance, or care from another family member, ranging from meeting personal and health care needs to providing instrumental and financial support (Lively, Friedrich, & Rubenstein, 2004; Pernice-Duca, 2010).

The burden of mental disorders on family members is often ignored, in part because given its subjective and personal nature, it is difficult to assess and measure (Shamsaei et al., 2013). Yet, a family member's serious mental illness has been reported to have a significant effect on family members' health, well-being, and quality of life (Angermeyer, Kilian, Wilms, & Wittmund, 2006; Fan & Chen, 2011; Møller, Gudde, Folden, & Linaker, 2009; Zauszniewski, Bekhet, & Suresky, 2009b; Zendjidjian et al., 2012). Indeed, research has shown that family members of persons with serious mental illness experience distress, anxiety, depression, and economic strain (Dore & Romans, 2001; Shamsaei et al., 2013; Tranvag & Kristofferson, 2008).

The research shows that 80% of those who provide care to persons with mental illness are women [World Federation of Mental Health (WFMH), 2010]. The family member who provides the help or support needed may be mother, wife, sister, daughter, aunt, or other, more distant relative (Chan, 2011; Dore & Romans, 2001; Weimand, Hedelin, Sallstrom, & Hall-Lord, 2010). Caring for a family member with serious mental illness may cause considerable psychological distress and adversely affect the mental health of women family members (Jiji, 2007; Zauszniewski et al., 2009b).

Although the literature is replete with studies describing the distress experienced by family members of persons with mental illness, the manner in which the distress is conceptualized and measured differs. For example, researchers have referred to the distress as psychological (e.g., Burns et al., 2013; Kim, Greenberg, Selzer, & Krauss, 2003; Mak & Cheung, 2012; Moller-Leimkuhler & Wiesheu, 2012; Remko, Stutterheim, Pryor, & Kok, 2013; Taylor, Greenberg, Selzer, & Floyd, 2008) or emotional (Dixon et al., 2011; Lucksted et al., 2013; Vaddadi, Gilleard, & Fryer, 2002); some did not describe the type of distress (e.g., Murray-Swank et al., 2007) and

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others have used the two terms interchangeably (e.g., Manguno-Mire et al., 2007). The multiple and diverse meanings that have been assigned to the distress experienced by family members of persons with mental illness make it difficult to capture their emotional status and to synthesize the research findings.

In addition, the distress experienced by family members of persons with mental illness has been operationalized mostly in terms of their inability to perform daily functions and their experience of specific psychological, somatic, and relational symptoms or behaviors using general measures of mental health; few have measured psychological distress using depression scales (e.g., Kim et al., 2003; Taylor et al., 2008). Most studies of psychological distress used the General Health Questionnaire (Goldberg, 1978) while most studies of emotional distress used the Brief Symptom Inventory (Derogatis, 1993). However, none of the studies of distress in family members of persons with mental illness have focused specifically on the examination of anxiety, depression, and anger as symptoms of emotional distress (Pilkonis et al., 2011) as the study reported here was designed to do.

EMOTIONAL DISTRESS AND CARING FOR THE MENTALLY ILL

Family members of those with serious mental illness suffer from significant negative emotions (Arksey, 2002, 2003; Ashworth & Baker, 2000). They worry about the future (Rose, Mallinson, & Gerson, 2006) and their relative's mental health (Hadrys, Adamowski, and Kiejna (2011) and they note feelings of tension and anxiety (Shankar & Muthuswamy, 2007). They struggle with sadness and grief (Rose et al., 2006), and they have been reported to be at risk for major depressive symptoms (Wittmund, Wilms, Mory, & Angermeyer, 2002).

For this study, emotional distress has been conceptualized as including anger, anxiety, and depression (Pilkonis et al., 2011). Studies of those negative emotions in family members of persons with mental illness have suggested that emotional experiences may vary depending on several factors, including their age, years of caregiving experience, relationship to the care recipient, and the stage of psychiatric illness of their relative (Karp & Tanarugsachock, 2000; Shankar & Muthuswamy, 2007). However, no studies have systematically examined the associations between women caregivers' anger, anxiety, and depression and the personal characteristics of the women, including age, race/ethnicity, and education; the characteristics of the person with the mental illness, including age, diagnosis, and time since first diagnosed; and features of the family situation, including the relationship between the caregiver and the person with mental illness, the residence of the mentally ill person (the same household or not), and receipt of direct, personal care by the family member or not.

The study reported here systematically investigated these associations using data from a larger study of women family members of adults with serious mental illness, whose results have been reported elsewhere (Zauszniewski, Bekhet, & Suresky, 2008, 2009a,b; Zauszniewski et al., 2009b). The larger study found that: (1) specific aspects of the woman caregiver, the person with mental illness, and the family situation were associated with perceived burden, resourcefulness, and quality of life (Zauszniewski et al., 2008); (2) perceived burden, resourcefulness, and quality of life were associated, but differed caregiver by race/ethnicity (Zauszniewski et al., 2009a); and (3) perceived burden and positive cognitions have direct effects on resilience indicators (Zauszniewski et al., 2009b). However, data on negative emotions collected in the larger parent study have not previously been examined. Analysis of such data is critical to providing a fuller picture of the emotional experience of women family caregivers.

This study therefore addressed the following research questions:

1. Is there an association between women caregivers' emotional distress (anger, anxiety, and depression) and the personal characteristics of those women (age, race, ethnicity, and education)?

2. Is there an association between woman caregivers' emotional distress (anger, anxiety, and depression) and the characteristics of the person with the mental illness (age, diagnosis, and time since first diagnosed)?

3. Is there an association between women caregivers' emotional distress (anger, anxiety, and depression) and the family situation (relationship between women family member and person with mental illness, whether the person with mental illness is living in the same household, and whether the person is receiving direct, personal care by the woman family member)?

METHODS

Design

Data for this exploratory, descriptive study were obtained in a larger cross-sectional study of female family members of adults with serious mental illness, which has been published elsewhere (Zauszniewski et al., 2008, 2009a,b). The original study was approved by the University Institutional Review Board.

Sample

The sample was composed of 60 women family members of adults who had a serious mental illness, defined as schizophrenia, bipolar disorder, major depressive disorder, or an anxiety disorder (see Zauszniewski et al., 2008, 2009a,b). To be included in the study, the women family members had to be between 18 and 65 years of age and able to read and understand English. They were recruited in northeast Ohio through advertisements posted in community mental health centers, local churches, and other venues, including grocery stores, department stores, restaurants, coffee houses, bookstores, libraries, and local support groups. The advertisement directed those who were interested in participating in the study to contact the researchers. The characteristics of the women family members, adults with mental illness, and family situation are summarized in Table 1.

The sample size for this secondary analysis was determined to be adequate based on a power analysis for examining descriptive trends reflecting substantial differences ($d = .80$) by grouping (i.e. categorical)

Table 1
Characteristics of Women Family Members, Mentally Ill Adults, and Family Situation.

Characteristics of women family members		
Age in years – mean (standard deviation)		46.28 (11.71)
Race/ethnicity – n (%)	African American	30 (50%)
	Caucasian	30 (50%)
Education level – n (%)	High school or less	14 (23%)
	Some college/associate degree	30 (50%)
	Bachelor's degree or higher	16 (27%)
Characteristics of person with mental illness		
Age in years – mean (standard deviation)		37.75 (13.96)
Years since first diagnosed – mean (standard deviation)		11.21 (9.65)
Diagnosis – n (%)	Anxiety disorder (panic)	1 (2%)
	Bipolar disorder	27 (45%)
	Depression	5 (8%)
	Schizophrenia	27 (45%)
Characteristics of family situation		
Relationship – n (%)	Mother	24 (40%)
	Sister	14 (23%)
	Other[a]	22 (37%)
Living arrangement – n (%)	In same household	24 (40%)
	In separate household	36 (60%)
Assistance – n (%)	Direct/personal care	41 (68%)
	Indirect/support	19 (32%)

[a] other = 4 aunts, 2 cousins, 7 daughters, 3 wives, 6 grandmothers.