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5-2012

In Their Own Voice: Family Caregivers Speak About Chronic Mental Illness

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In Their Own Voice: Family Caregivers Speak About Chronic Mental Illness

Submitted by Emily E. Ross, BSW, LSW
May 9th, 2012

MSW Clinical Research Paper

The Clinical Research Project is a graduation requirement for MSW
students at St. Catherine University/University of St. Thomas School of
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university Institutional Review Board, implement the project, and publicly
present their findings. This project is neither a Master's thesis nor a
dissertation.

School of Social Work
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Abstract

The shift in the United States' treatment of individuals with chronic mental illnesses from a hospital to community-based system, a process that has come to be known as deinstitutionalization, has markedly impacted mental health service delivery. Family members of people with a chronic mental illness have often had to assume critical caregiving roles in order to provide care to their relatives with a chronic mental illness within the context of their own community. This study examined the needs of family members, often referred to as family caregivers, who have a relative with a chronic mental illness for whom they provide care. Family members were recruited through the National Alliance of Mental Illness' (NAMI) Family-to-Family Program and NAMI newsletter. Using a qualitative design, five family caregivers discussed their needs in their role as a family caregiver to someone with a chromic mental illness, and how they have been able to get these needs met within the context of the current mental health system. Family caregivers experienced both benefits and burdens due to their role in their family member's life. Benefits included an increased sense of compassion for others with chronic mental illness, an expanded knowledge base about mental health issues, and a personal sense of reward and accomplishment. Participants identified burdens associated with their role as family caregiver such as increased levels of stress, worry, and sadness and strained relationships. Participants noted that limited amounts of time inhibited their ability to serve effectively in their role, and highlighted the importance of having social support and case management services. Participants spoke highly of their experience with the NAMI Family-to-Family program. They identified other resources through which they have gotten their needs met in their role as a family caregiver and provided suggestions to improve service delivery.

Acknowledgements

I would like to thank the chair of my research committee, Dr. Carol Kuechler, for her ongoing support and guidance through this research process, which so often seemed incredibly daunting. Her unwavering high standards for my research, and her continual encouragement, provided me with the motivation I needed to be successful in the completion of this work.

I am also exceptionally grateful to my research committee members, Sandy Parnell and Catherine Roach, for the care with which they reviewed my work and their frequent words of inspiration. Sandy, a professor from my undergraduate education and one of my social work role-models, and Catherine, a stranger whose path I crossed and who did not hesitate to share her compassion and knowledge for the mental health field with me, have both played critical roles in my ability to execute this research process effectively, professionally, and thoughtfully.

A heartfelt thanks to my family, for letting me live in their basement and raid their refrigerator on a regular basis. Also, for providing me with an overwhelming amount of love and kindness as I navigated my way through my graduate education.

Most importantly, I would like to thank the St. Catherine University/University of St. Thomas' School of Social Work, my social work family, for the education I have received throughout my undergraduate and graduate education. The impact that this program has had on me as a social worker and as a human being is tremendous and will never be forgotten.

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Introduction

The Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 (U.S. Congress, 1963) is widely regarded as the catalyst for deinstitutionalization (Day, 2006; Roberts & Kurtz, 1987). In the United States, the major shift in the treatment of individuals with a chronic mental illness from a hospital-based to a community-centered model has impacted all facets of the mental health system, as well as society as a whole. An unintended consequence of this dramatic shift to community-based care is that individuals who care for those with chronic mental illnesses, such as close friends and family members, must assume a critical caregiving role (Thompson & Doll, 1982; French, 1987; Lamb & Bachrach, 2001; Segal, 1979; Morell, 1979; Tabayabaina, 2003; Roberts & Kurtz, 1987).

In the process of moving to community based care, those who provide care to people with chronic mental illnesses have actually become, sometimes unknowingly, pivotal members of the individual's mental health team. These friends and family members often bear the daily responsibility of caring for and coping with someone who has a chronic mental illness (Thompson & Doll, 1982). People who care for someone with a chronic mental illness, whether they be a family member, close friend, or otherwise, are essential partners in a client's support system and serve as a buffer against mental health relapses (Riebschleger, 1991).

The cost of not having members of an individual's support system to care for someone with a chronic mental illness is tremendous. Extensive amounts of additional public resources are required in order to provide services without the assistance and contributions of the individual's support system (Goodman, 2004; Lamb & Bachrach, 2001).

If members of an individual's support system have been required to take on a critical caregiving role for people with a chronic mental illness, some of society's most poor and

vulnerable members, then society must make sure it is attending to the needs of those who care for people with chronic mental illnesses (Dixon et al., 2011). According to Dixon (2010), without the involvement of family caregivers, individuals will ultimately experience more mental health relapses and require more frequent hospitalizations and other crisis services. These consequences would negate the purpose of community-based care, which sought to humanize mental health care by offering services within the community. In addition, people who care for a person with a mental illness will be better able to care for themselves and the individual they care for if they are able to easily obtain adequate support and resources to assist them in serving effectively in their role (Goodman, 2004).

Social workers will often be in a position where they are expected to interact with or provide direct care to caregivers of people with a chronic mental illness, making this particular topic especially critical for further exploration (Segal, 1979). Social workers have an opportunity to engage these caregivers in a way that not only promotes the individual's wellness, but also the overall wellness and functioning of the family or group within which the individual exists (Riebschleger, 1991).

The purpose of this study is to explore the experiences, needs, and supports used by family caregivers for people with a chronic mental illness and to determine how these individuals utilize resources in order to get their needs met and serve effectively in their role. Past and current participants in the National Alliance on Mental Illness' (NAMI) Family-to-Family Program were invited to participate in the study, as well as recipients of the NAMI monthly newsletter.

Literature Review

In this review of the current literature on the experiences, needs, and interventions for family members and other non-professional caregivers of individuals with a chronic mental illness, the intended and latent consequences of deinstitutionalization will be reviewed, as well as the impact of deinstitutionalization on families. The researcher will present findings on the role of the family caregiver, challenges and benefits of family caregiving, and interventions to aid family caregivers in serving effectively in their role. A detailed history of mental health treatment can be found in Appendix A.

The literature uses both the terms "family caregiver" and "family members of individuals with a chronic mental illness" in reference to family members who are involved in the care of a relative with a chronic mental illness. This will be reflected in the following review by the interchangeable use of these terms.

Deinstitutionalization

This section will outline the primary historical events and political movements that resulted in the implementation of deinstitutionalization. It will outline both the intended and latent consequences of the shift from institutionally-based to community-centered mental health care. This section will also review the impact that deinstitutionalization had on families of individuals who have a chronic mental illness.

In 1962, President John F. Kennedy established a mental health panel that created and presented the Community Mental Health Act (Mental Retardation Facilities and Community Mental Health Centers Construction Act) to Congress in 1963 (Day, 2006; U.S. Congress, 1963). This act initiated the construction of community mental health centers, comprehensive services

for individuals with mental illnesses, and funding for the training of social workers in the mental health field (Day, 2006; U.S. Congress, 1963).

When Medicare and Medicaid were introduced in 1960, the federal government began to assume a heightened level of financial responsibility for the cost of mental health care (Roberts & Kurtz, 1987). The implementation of the Supplemental Security Income program in 1974 perpetuated this trend of the federal government's financial contribution to mental health care (Day, 2006). Throughout the 1960s and 1970s, the need for comprehensive community mental health care was advocated for through several state and national policies (Day, 2006).

The goal of deinstitutionalization was to reintegrate individuals with chronic mental illnesses back into the community where they might be able to increase their quality of life (Lamb & Bachrach, 2001; Talbott, 1979; Day, 2006; Roberts & Kurtz,1987) and move towards a realistic level of independence. Community-based care for persons with mental illnesses encompasses a variety of services, such as outpatient clinics, halfway houses, residential living facilities, residential treatment programs, day treatment, and adult foster care (Anderson & Lynch, 1984).

In 1955, there were 559,000 patients in state mental hospitals in the United States. By 1998, there were 57,151 people occupying beds in state psychiatric hospitals. It can be assumed that the notable decrease of individuals receiving inpatient psychiatric care was the result of deinstitutionalization (Lamb & Bachrach, 2001; Talbott, 1979).

Lamb and Bachrach (2001) noted that deinstitutionalization of individuals with mental illness involved three specific and distinct components: (1) the release of individuals with mental illness from hospitals into the community; (2) avoidance of the admissions of persons with

mental illness to a hospital-based inpatient setting; and (3) the development of alternative community services to provide for individuals with chronic mental illness.

Intended and latent consequences of deinstitutionalization

The shift in the United States' treatment of individuals with chronic mental illnesses from a hospital-based to community-centered system, a process that has come to be known as deinstitutionalization, has markedly impacted the mental health service system. While many individuals with chronic mental illnesses are no longer institutionalized, many of them face new struggles such as homelessness, unemployment, and difficulties accessing mental health care services (Thompson & Doll, 1982; French, 1987; Lamb & Bachrach, 2001; Segal, 1979; Morell, 1979; Tabayabaina, 2003; Roberts & Kurtz, 1987).

Bradshaw, Armour, and Roseborough (2007) asserted that goals of deinstitutionalization for community integration have not been fulfilled because individuals with chronic mental illnesses have become socially isolated due to the move to community-based care. Segal (1979) identified that the social isolation of individuals with chronic mental illnesses was directly related to mental health relapse and the need for institutionalization/ hospitalization. French (1987) asserted that the social isolation created by the implementation of deinstitutionalization had resulted in making individuals with chronic mental illness more susceptible to the hostility of the larger society.

Lamb and Bachrach (2001) disagreed, noting that persons with chronic mental illness have actually benefited from community-based services. They stated that upon being reintegrated into the community, many individuals with a chronic mental illness have been able to live independently and even maintain employment.

It was assumed by politicians and other community stakeholders that community-based care would also prove to be more cost-effective (Lamb & Bachrach, 2001). Current cost estimates associated with serious and persistent mental illnesses, which affect 6 percent of the United States' population, is over $300 billion annually (National Institute of Mental Health, 2002). In 2006, it was estimated that 36.2 million Americans paid for mental health services, totaling upwards of $57.5 billion. This results in an average individual expense per person of $1,591 (Agency for Healthcare Research and Quality, 2006).

In 2008, 13.4 percent of all adults in the United States received treatment (inpatient or outpatient treatment settings and/or prescription medication for mental health diagnoses) for a mental health concern (National Survey on Drug Use and Health, 2008). However, only 58.7 percent of the adults with a serious and persistent mental illness received some sort of professional treatment for their mental illness. This statistic shows that a notable amount of United States citizens who are diagnosed with a serious and persistent mental illness have *not* received the critical care they need to survive and thrive in society.

The impact of deinstitutionalization on families

Since the early 1970s, significant efforts have been directed towards closing and downscaling institutions that aim to care for individuals with disabilities and/or mental illness. (Tabatabaina, 2003). Deinstitutionalization has resulted in families acquiring the responsibility of caring for their relatives with chronic mental illness.

Schodek, Liffiton-Chrostowski, Adams, Minigan, and Yamaguchi (1980) argued that deinstitutionalization was developed based on the belief that the best way to care for individuals with mental illness was to receive supportive services from their families and communities. They assumed that family members would serve as the most effective advocates for their family

member with a mental illness since they would have the most accurate insight into their mental illness and day-to-day strengths and limitations. Despite this, Schodek et al. (1980) noted that no procedure or programming was created to inform and educate families about the new roles that would be required of them with the implementation of deinstitutionalization.

The movement to community-based care mandated that family members of individuals with mental illness step into a critical caregiving role (Thompson & Doll, 1982; Goodman, 2004). Family care and support was considered to be an essential element in the efficacy of community-based mental health care (Cummings & MacNeil, 2008). Cummings and MacNeil (2008) found that family members of adults with chronic mental illness frequently engage in caregiving tasks such as helping their relative with shopping, transportation, meal preparation, and money management. Other tasks family members offer assistance which include additional activities of daily living such as grooming and bathing (Cummings & MacNeil, 2008).

Anderson and Lynch (1984) went so far as to argue that deinstitutionalization has strained, at times even exhausted, the resources of family members of individuals with a chronic mental illness. Aschbrenner, Mueser, Bartels, and Pratt (2011) concluded that adults with mental illnesses who have the most limited functioning require consistent contact with their family members in order to exist safely in the community. They suggested that this can exhaust the resources of family members, leading to burnout and dissatisfaction (Aschbrenner, et al., 2011).

A study by Tabatainia (2003) cited four primary reasons that many families were opposed to deinstitutionalization: (1) concern for the adverse impact on their own lives; (2) concern for the adverse impact on their relative's life; (3) perceived inadequacy of community-based residential services; and (4) the belief that services provided in institutionalized settings were and would continue to be helpful and conducive to the wellness of their relative. Family

members who participated in this study identified that hospitalization was at times a beneficial and necessary service for individuals who struggle with a mental illness (Tabatainia, 2003).

Role of Family Caregiver

For this literature review, family caregiver will be defined as a mother, father, adult child, stepmother, stepfather, husband, wife, domestic partner, sibling, grandparent, aunt, uncle, or cousin who assumes the task of providing regular care to their relative with a chronic mental illness. It should be acknowledged that many individuals with a mental illness possess caregivers outside of the family unit, who assume the same role as that of a family member. This section will outline challenges associated with family caregiving. More specifically, benefits and burdens associated with family caregiving will be addressed.

Benefits of family caregiving.

The family's experience of having a loved one with a mental illness at home has been studied since the late 1950s. Early research suggested that adopting the role of caregiver for an individual with a chronic mental illness took a small toll on the caregiver (Ferris & Marshall, 1987). Thompson and Doll (1982) asserted that this research was problematic in that it assumed an absence of stigmatizing beliefs towards individuals with mental illness translated into little burden experienced by the family unit.

However, some research affirmed the findings of earlier research, concluding that family caregivers experience some benefits from being in the caregiving role of their relative with a chronic mental illness (Cummings & MacNeil, 2008). Cummings and MacNeil (2008) found that over half of family caregivers for individuals with a chronic mental illness indicated they "often" had positive interactions with their relative with chronic mental illness. Similarly, family members in the study reported feeling appreciated because of their involvement in their relative's

life and found enjoyment and personal satisfaction in their caregiving role and associated tasks (Cummings & MacNeil, 2008).

Challenges of family caregiving

For a long time, families were seen as possessing an etiological role in the development of the mental illness of a loved one. During the 1950s it was largely determined by researchers that the cause of chronic mental illness was associated with features of family life, communication styles, or personality patterns. With this, the family was viewed as the "cause" of a loved one's illness (Ferris & Marshall, 1987; Hatfield; 1981; Goodman, 2004).

Goodman (2004) asserted that empirical research had not supported theories of family etiology of mental illness. Goodman (2004) reported that some mental health providers continued to view the family through a disparaging lens, which ultimately inhibited effective service delivery (Goodman, 2004).

Goodman (2004) also acknowledged the profound stigma experienced by family members of individuals with mental illness. Many family members experienced isolation and exclusions from neighbors, friends, and extended family members because of this stigma. The assumption that families played an etiological role in the mental illness of a loved one further perpetuated this stigma (Goodman, 2004).

Caregiver burden. Thompson and Doll (1982) found that 73% of families who have a relative with a mental illness reported being adversely affected in one or more ways due to providing care for their loved one. In this same study it was found that 27% of families reported bearing a "severe" burden due to their caregiving role.

The concept of burden among family caregivers for individuals with mental illness can be divided into two categories: objective burden and subjective burden. Objective burden relates to

practical hardships such as assisting in daily activities, disruption of family functioning, or financial strain due to care services. Subjective burden refers to psychological and emotional distress experienced by family caregivers. Examples of subjective burden include tension, anger, guilt, or shame due to stigma surrounding mental illnesses (Goodman, 2004; Thompson & Doll, 1982; Cummings & MacNeil, 2008).

Feelings of embarrassment, responsibility, shame, guilt, and hopelessness are common for family caregivers (Ferris & Marshall, 1987; Goodman, 2004; Marley, 1992). Parents often reported experiencing difficulties managing the subjective burdens of caring for a loved one with mental illness (Goodman, 2004).

Marley (1992) addressed specific aspects of serious and persistent mental illness that may be burdensome to family caregivers. He stated that family caregivers might be accused by their family member of causing hallucinations or delusions. He noted that family caregivers might be asked to listen to and/or validate details of psychotic experiences (Marley, 1992).

Thompson and Doll (1982) concluded that there was a universality of emotional burdens experienced by families of loved ones with mental illness despite factors such as family composition, social class, and race. A study by Stueve, Vine, Elmer and Struening (1997) investigated perceived burden among black, Hispanic, and white groups of caregivers of adults with serious mental illness. They determined that while there was no statistically significant difference in perceived burden between Hispanic and white caregivers, black caregivers tended to report less burden than other groups. Stueve et al. (1997) concluded that this was due to increased levels of social support and religious involvement in the black community.

Caring for an individual with a chronic mental illness also requires a notable financial commitment (Goodman, 2004; Morell, 1979; Segal, 1979; Thompson & Doll, 1982; Lai &

Thomson, 2011). Medical insurance may not cover certain types of treatment or medications. The family may be put in the position of having to fund these components of treatment for their loved one with a chronic mental illness. Some chronic mental illnesses also manifest themselves by way of destructive spending habits or difficulty with budgeting/money management, providing another way that family members of individuals with a chronic mental illness might experience financial hardship (Goodman, 2004).

Anderson and Lynch (1984) found a significant relationship between the social climate of the family unit and the frequency of interaction between the family and the member with a chronic mental illness. They concluded that as families interacted more frequently with their loved one who had a chronic mental illness, there was less integration and cohesion between the family members; family opportunities became more limited; the family fostered a heightened level of negative feelings towards their loved one with a chronic mental illness, and the family experienced a lessened amount of social support. In essence, the more frequently individuals with a chronic mental illness interacted with their family, the more stress was experienced by the family unit (Anderon & Lynch, 1984).

Interventions

This section will review current interventions available to aid family caregivers in serving effectively in their role. Interactional and educational interventions will be addressed. NAMI's Family-to-Family Program, an example of an educational intervention for family caregivers, will be discussed as well.

Studies have noted the minimal services available to meet the needs of families caring for a loved one with a mental illness (Cummings & MacNeil; Morell, 1979). Cummings and

MacNeil (2008) found that family caregivers for adults with a chronic mental illness had limited resources for dealing with their caregiving responsibilities.

Tabatabainia (2003) noted that families of individuals with a chronic mental illness face great challenges as they try to sustain a safe, caring, respectful, and supportive environment for their loved one. Ferris & Marshall (1987) identified that families require support in order to adequately serve in their role of caregiver for individuals with a mental illness (Ferris & Marshall, 1987).

Anderson and Lynch (1984) asserted that there was a critical need for cohesiveness and support within a family, in order to minimize and prevent the stress experienced by families with a member who has a chronic mental illness. Tabatabainia (2003) reported that family members of individuals with a chronic mental illness experienced feelings of confusion, and possess a lack of knowledge about how to reintegrate their loved one into the community following a long-term stay in a hospital-based, inpatient mental health setting.

A study conducted by Drier and Lewis (1991) explored the difference in effectiveness between educational and interactional models of interventions for family caregivers of individuals with chronic mental illness. They concluded that a combination of psychoeducation and support services were the most beneficial to assist families in effectively coping with having a relative with a chronic mental illness. Parents of children with chronic mental illnesses who were interviewed in this study stated that after receiving both models of intervention they felt better about themselves and their ability to effectively care for their children (Drier & Lewis, 1991).

Some studies have explored specific areas of intervention for family caregivers of individuals with chronic mental illnesses. Important areas for family intervention include

diagnosis, psychotropic medications, community resources (including housing, occupational/vocational assistance, crisis services, social/recreational opportunities), and therapy techniques (Walsh, 1988; Ferris & Marshall, 1987).

Interactional interventions

Mutual help and other support groups are helpful in providing support for families with loved ones who have a chronic mental illness. (Anderson & Lynch, 1984; Walsh, 1988; Hatfield, 1981; Ferris & Marshall, 1987; Goodman, 2004; Dreier & Lewis, 1991; Cook, Heller, & Pickett-Schenk, 1999). Many self-help organizations provide peer-led support groups, such as the National Alliance for the Mentally Ill (NAMI), National Depressive and Manic Depressive Association, Schizophrenics Anonymous, RECOVERY, the Federation for Families, and GROW (Cook et al.; 1999).

Mutual aid and self-help groups for families of loved ones with mental illness have grown rapidly since the move to community-based mental health services (Hatfield, 1981). Caregivers come to support groups to share experiences, to speak about coping skills, to exchange information, to obtain education, to receive validation, and to gain access to new resources (Goodman, 2004).

Lai and Thompson (2011) found that adequate levels of social support among family caregivers of adults with chronic mental illnesses resulted in decreased feelings of caregiver burden. Lai and Thompson (2011) indicated that social support provided family caregivers with an outlet for concerns and stress associated with their role of being a family caregiver.

Group support can expand a caregiving family's social network and provide a venue for them to express their various feelings and desires. Support groups also provide an opportunity for families to have positive interactions with mental health professionals (Goodman, 2004).

Crisis groups can be helpful for family caregivers as well (Ferris & Marshall, 1987). Crisis groups provide support to families who are having their first encounter with mental illness or who are in a crisis period where they require additional support. Ferris and Marshall (1987) estimated that families who are newly experiencing a loved one with mental illness need up to six weeks to process and sort through feelings associated with the event.

Dreier and Lewis (1991) stated that traditional groups that utilize a psychoanalytic framework are unhelpful in serving families of adults with chronic mental illnesses. They explained that psychoanalytic principles suggest that by helping people understand how they feel, they will feel better and thus, change their behavior. Dreier and Lewis (1991) explained that mental health workers have found that simply understanding problems and expressing feelings does not provide sufficient support for family members of individuals with severe psychosocial problems.

Educational interventions

Solomon, Draine, Mannion, and Meisel (1997) explained that the goal of educational programs for family caregivers is to teach coping skills that promote family self-efficacy. These classes are structured, educationally-based programs that assist families in understanding their loved one with mental illness and developing tools to assist them in day-to-day life. Educational groups can assist parents in becoming less critical of their loved one with a chronic mental illness, which in turn benefits the community and the individual (Goodman, 2004).

Education is an important component of providing families of individuals with a chronic mental illness with the tools to assist in the provision of care for their loved one (Ferris & Marshall, 1987; Tabatabainia, 2003). Dreier and Lewis (1991) asserted that family caregivers need the same training as mental health professionals in order to serve effectively in their role.

Dreier and Lewis (1991) stated that when family members received information about their loved ones' diagnosis, as well as strategies to assist in managing the illness, feelings of mastery increased, while feelings of blame towards their family member and personal feelings of guilt decreased.

Ferris and Marshall (1987) identified important topics for education intervention to equip family members with sufficient information to care for their loved one with chronic mental illnesses. These topic areas include education about the nature and management of mental illness, communication techniques, and problem-solving skills.

Solomon et al. (1997) spoke about barriers that were encountered when engaging family members of individuals with a chronic mental illness in educational programs. They reported that if their relative's mental health appeared to be stable, they were less likely to seek out support because their level of "need" was perceived as lessened. Dreier and Lewis (1991) also spoke about barriers to providing educational interventions to family members of people with a chronic mental illness. They identified that it may be difficult to engage family members in psychoeducational programs because family members may feel intimidated or overwhelmed by the task of caring for a loved one with chronic mental illness.

Tabatabainia (2003) suggested that families would benefit from behavioral supports to assist them in addressing and managing problematic behaviors associated with having some mental illnesses. He asserted that this type of support would help family members effectively manage and modify problematic behaviors of their loved one within the home by providing them with skills and strategies to assist them in their day-to-day interactions with their loved one who has a mental illness.

Solomon et al. (1997) discussed the importance of connecting family members of individuals with chronic mental illness to case managers. Case managers might be able to assist families in caring not only for their relative with a mental illness, but also by connecting families and individuals with a mental illness to resources outside of the home that might assist the client and families in getting their needs met.

Chen (2008) identified several positive outcomes of future care planning, the process of families preparing for the future wellbeing of their loved one with a chronic mental illness. Future care planning can be considered another educational intervention for families of adults with a chronic mental illness. Future care plans include residential and financial arrangements, as well as means of practical support for the individual experiencing mental health challenges. They can be created by family caregivers in collaboration with their loved one who has a chronic mental illness. In his qualitative study of caregivers who used future care planning workshops, Chen (2008) demonstrated that the plans helped reduce family stress, decrease levels of apprehension about the future, and increase family members' level of confidence regarding plans for the future. Chen (2008) suggested that future care planning can be especially useful for aging parents who assume the role of caregiver for their son or daughter with chronic mental illness, by alleviating concerns about their child's life after they are no longer able to provide them with regular care. This, in turn, positively impacts the individual with mental illness due to lessened levels of ambiguity, anxiety, and fear (Chen, 2008).

National Alliance on Mental Illness' Family-to-Family Program. An example of an educational program that targets families of individuals with chronic mental illness is the National Alliance of Mental Illness' Family-to-Family program. This is a 12-week intensive course that is taught by trained family caregivers. The course is free to participants and available

nationwide. Over 300,000 family caregivers have graduated from this program. The course includes current information about different mental illnesses, medications, the etiology of mental illnesses, crisis management techniques, early intervention and relapse prevention strategies, caregiver self-care, as well as information regarding current advocacy initiatives pertaining to mental health (National Alliance on Mental Illness, 2011).

A study by Dixon et al. (2011) evaluated the effectiveness of this program and found that participants had notable improvement in problem-focused coping, as measured by feelings of empowerment and knowledge about mental illness. Participants also demonstrated enhanced emotion-focused coping abilities measured by their increased feelings of acceptance for their family member's mental illness, reduced stress levels, and improved problem-solving strategies (Dixon et al., 2011).

A study conducted by Cook et al. (1999) explored whether participation in a National Alliance for the Mentally-Ill support group impacted family caregiver burden. The study concluded that caregiver burden was significantly lowered by participation in the support group.

Connection to Social Work

There are few direct ties to social work practice in the literature on the experiences, needs, and services for families of individuals with a chronic mental illness. Studies do, however, provide recommendations for mental health professionals. Dreier and Lewis (1991) asserted that clinical mental health workers are increasingly expected to engage family members of individuals with mental illness as allies in the treatment process.

Despite the social work profession's focus on environmental and systemic factors impacting the functioning of their clients, social work practice for individuals who have chronic mental illnesses is frequently targeted solely at the client themselves. The needs of the

individual's family are often not a target of treatment (Johnson, 1998). Social workers possess a unique capability to use their skills working with the person-in-environment framework for practice to help families of people with a chronic mental illness progress in their recovery process, as well as avoid full blown mental health relapses (Riebschleger, 1991).

Social workers must be informed of the needs of family members of individuals with a chronic mental illness. With this information, they will be able to assist family caregivers in managing and finding fulfillment in their roles.

The purpose of this study was to explore the needs of individuals who care for someone with a chronic mental illness and to identify ways in which they use supports such as the National Alliance on Mental Illness' Family-to-Family Program to assist them. This information will be shared with social workers to help them understand the needs of those who care for individuals with mental illnesses in order to assist them in serving more effectively in their roles.

Conceptual Framework

A conceptual framework serves as a guide for the research process. The conceptual framework used for this study was the strengths perspective. The strengths perspective is an orientation or philosophical lens that assumes the presence of positive and constructive elements of all human beings, even in the challenging and complex situations (Miley, O'Melia, and DuBois, 2007). The strengths perspective emphasizes the importance of looking for client strengths and utilizing them during the helping process in order to promote clients' goal achievement (Saleebey, 2006).

Many practice models in western medicine utilize frameworks that place a greater focus on client limitations and pathology. In such approaches, client strengths may be overlooked. Miley, O'Melia, and DuBois (2007) asserted that pathological frameworks diminish the

likelihood of positive change by establishing negative expectations. This might hinder the ability to be successful in the helping process. It is important to counterbalance an assessment of an individual's limitations with an emphasis on their strengths (Sheafor & Horejsi, 2008).

Resilience, a component of the strengths perspective, is the ability to experience adverse situations and maintain or add to one's personal power and strengths (Saleeby, 2006; Miley et al., 2007). Applying work by Miley et al. (2007) on resilience, it is evident that families of individuals with a chronic mental illness face many challenges in their role as a caregiver, however they often utilize their own resilience to get their needs met.

This study built upon and explored the challenges *and* benefits to serving as a caregiver for a family member with a chronic mental illness. Research question #3 (Appendix D) asked participants to identify benefits they have felt or received based on their role in their family members' life. Research question #4 asked participants to identify challenges or burdens experienced in this role.

This study also investigated the needs and supports of family members with a relative who has a chronic mental illness. Research question #7 provided participants with an opportunity to identify their current needs in their role. This study also included opportunities for participants to identify how they have met these needs. Research question #9 prompted participants to identify how their participation in the National Alliance on Mental Illness' Family-to-Family Program has helped them address their identified needs as a family member of someone with a chronic mental illness. Question #10 asked participants what, if any, other supportive services have assisted them in meeting their needs.

Despite challenges associated with the role of being as family caregiver, many caregivers are able to find a way to get their own needs met in order to ensure their own wellness and that

they are providing adequate care to their loved one. The strengths perspective focuses on activating resources as opposed to correcting deficits (Miley, O'Melia, & DuBois, 2007). Miley, O'Melia, and DuBois (2007) assert that human beings naturally strive to be compatible with their environment. It is important that social workers are mindful of the ways in which people have adapted to their environments in efforts to address challenges within those environments.

This study explored how family caregivers are managing challenges associated with their role in order to maintain their own wellness and serve as a positive support to the person in their lives with a mental illness. This study explored resources that have been utilized by participants in order to assist them in getting their complex needs met.

Method

This study explored the experiences, needs, and supports used by family members of individuals with a chronic mental illness. Family caregivers were identified from participants in the National Alliance on Mental Illness' (NAMI) (Appendix B) Family-to-Family program as well as from recipients of NAMI's monthly electronic newsletter. Data for this qualitative study was gathered through semi-standardized interviews. Interviews were audio-recorded for the purpose of data analysis and to record and report the authentic voices of family members of individuals with chronic mental illness.

Sample

The sample for this study included adult family members of individuals with chronic mental illnesses who have or are currently participating in the National Alliance on Mental Illness' (NAMI) Family-to-Family program, or individuals who receive the NAMI monthly electronic newsletter. NAMI provided permission to use the Family-to-Family program and monthly newsletter as a vehicle for recruiting research participants (Appendix B). This

population was chosen because of NAMI's strong reputation for family education in the local community and due to their recognition as a positive educational intervention in a review of the current literature. While the researcher had hoped for 8 – 10 adult caregivers of individuals with chronic mental illnesses, 5 people participated in the study.

Participants were recruited using a two-step sampling method. Based on the agreement and process approved by the National Alliance on Mental Illness (NAMI), the researcher provided flyers (Appendix C) to NAMI. The NAMI state office distributed the flyers through e-mail to facilitators of NAMI Family-to-Family groups to distribute to their group members. NAMI also posted information about the study in their monthly electronic newsletter in order to recruit additional participants who may not be actively engaged in a Family-to-Family program presently.

Interested participants were asked to contact the researcher via email or phone for further information about the research and/or to participate. At that time, the researcher conducted a participant eligibility screening by ensuring that the potential participant was over the age of 18 and had a family member with a chronic mental illness. If the participant fit the screening criteria and was interested in participating, the researcher set up a time to meet the participant individually. Due to scheduling difficulties, 80% of the research participants requested to have their interview times with the researcher rescheduled between one and four times.

The consent form (Appendix D) and interview guide (Appendix F) were reviewed with each participant at the time of the interview. The purpose of the study was also explained at this time.

Prior to the beginning of the interview, the researcher assessed that all participants understood what he/she had been asked to do through their participation in the study. The

researcher verified participants' understanding by asking three specific questions: (1) What is the purpose of the study?; (2) What procedures will you be asked to go through as part of this study? ; and (3) What can you do if you feel uncomfortable answering a question?

Protection of Human Participants

This study was reviewed and approved by the research committee and then presented to the St. Catherine University's Institutional Review Board. This project was submitted for review at the IRB meeting on December 1st, 2011. Engagement in this mandatory review served to ensure the protection of human research participants.

There were minimal risks involved in participating in this study. Based on the questions, participants may have experienced emotional discomfort, which was disclosed to participants in the research consent form (Appendix D). Participants were informed that they could stop the interview at any time, take a break from the interview, or skip questions posed to them by the researcher. The researcher also provided participants with resources to utilize should they wish to discuss any emotions that came up during or after the interview (Appendix F).

There were no direct benefits for participating in this study. It is possible that research participants could indirectly garner a personal sense of satisfaction from knowing that their experiences and opinions were used to increase the knowledge base for social workers working in the mental health field.

In order to maintain the confidentiality of research participants and materials, all consent forms were kept in a locked file in the researcher's possession. Audio-recorded interviews and interview transcriptions were kept on the researcher's personal computer that requires a secure password for access. All names and other identifying information of participants were known only by the researcher. The researcher was the only person who listened to the audio-recording.

Transcriptions were created from the audio-recording and did not include names or identifying information of the participants. No outside transcription services were utilized. Published results of the data are anonymous in order to maintain participant confidentiality. The audio-recordings and any records with names of participants were kept by the researcher on a personal computer that requires a secure password for access, or in a locked file in the researcher's possession until the research had been analyzed and presented as a requirement of the St. Catherine University/University of St. Thomas Master of Social Work Program, on May 14th, 2012. All audio-recordings and other identifying research materials were destroyed no later than June 1st, 2012.

Data Collection

Instrument development.

The interview consisted of demographic questions, followed by a series of open-ended questions (Appendix E). Interview questions were developed based on a review of current literature regarding the needs of family members of individuals with chronic mental illness, as well as information about the curriculum of the National Alliance on Mental Illness' Family-to-Family program.

Data collection process.

Once willing research participants were identified, it was difficult for the researcher to schedule times to meet with research participants. Participants had busy schedules and frequently needed to reschedule interview times to accommodate their personal commitments.

Data was collected in face-to-face interviews that took approximately 45 minutes to one hour. All interviews were audio-recorded. The interviews were held in mutually agreed-upon private locations such as community center meeting rooms or library meeting rooms. In order to

ensure the protection of human subjects, all identifying information was known only by the

researcher. Consent forms were kept in a locked file to which only the researcher had access.

Audio-recorded interviews and transcriptions were kept on the researcher's personal computer

that required secure password access. No outside transcription services were used. All audio-

recordings and other identifying research materials were destroyed no later than June 1st, 2012.

Data Analysis

In order to analyze the data, the interviews were transcribed and content analysis was

used in order to identify and explore themes in the data. Berg (2009) describes content analysis

as a "careful, detailed, systematic examination of a particular body of material in an effort to

identify patterns, themes, biases, and meanings" (Berg, 2009, p. 338). Content analysis is used

in a wide array of professions – primarily with human communications (Berg, 2009).

In particular, the researcher sought to understand participants' views about their needs

and supports related to their roles as caregivers for a family member with a chronic mental

illness. The use of the qualitative research technique has strengths and limitations. Qualitative

research is exploratory, thus enabling information that is detailed and complex. Qualitative

methods focus on what people feel and how they think. Some disadvantages to using qualitative

research methods are that the findings cannot be quantified or generalized to a broader

population (Monette, Sullivan, & DeJong, 2008; Berg, 2009).

In order to identify research themes, the researcher listened to the interview recording at

least twice in order to gain a strong sense of the data. The researcher color-coded transcripts in

order to differentiate participant responses. The researcher reviewed completed transcriptions

and noted common themes in the margin. After this, the writer compiled quotes from the

transcriptions into a larger document for each identified theme. Quotes from participant

responses will be printed in italics in the Findings section below. The use of qualitative research in this study provided an opportunity to explore and document the distinct voices of family members who have a family member with a chronic mental illness.

<div align="center">**Findings**</div>

This study explored the complex needs of family members who care for an individual who has a mental illness, as well as how they are getting these needs met in order to serve effectively in their role. This section begins with a description of the participants who were interviewed for the sake of this study. Immediately following this, themes identified from interviews with research participants will be reviewed. Participants identified benefits and burdens experienced due to their role in the life of their relative with a chronic mental illness. Finally, participants spoke about services that have assisted them in getting their needs met in their caregiving role. Participants also identified services and interventions that would be helpful to assist them in serving more effectively in their role.

Description of Participants

Despite recruitment efforts, the researcher experienced difficulty identifying individuals who were able to serve as participants for this study. A total of eight people expressed interest in the study and five interviews were conducted. The three individuals who expressed interest in the study but who were unable to contribute, cited logistical reasons such as time commitments and living at a distance to the researcher as a barrier to their engagement in the study.

A total of five participants were interviewed for the sake of this study; four were women and one was male. Participants identified themselves as mothers, fathers, daughters, sisters, and grandmothers to an individual in their life with a chronic mental illness. While not asked to disclose their age, all participants appeared to be over the age of 30 and under the age of 50. All

five research participants reported that they had been serving in their role as a caregiver to their family member for at least two and a half years.

All five interviewees were recipients of the NAMI monthly newsletter. Four of the five participants had participated in the NAMI Family-to-Family program and had completed the curriculum. The other person has participated in a community-based crisis support group for family caregivers.

Benefits

All research participants were able to identify benefits associated with their role as a family caregiver. Several of the participants expressed surprise when the researcher prompted them to identify benefits received or felt due to their role as a family caregiver. One participant said, *Wow, I would have never used that word, 'benefits', but they're very tangible. You can see them in your own life.* Specific benefits associated with family caregiving that were identified by participants were: heightened sense of compassion for others, increased knowledge base, and a sense of personal growth and reward.

Several participants identified having a heightened sense of compassion for others in the world around them due to their role as a family caregiver for someone with a chronic mental illness. One caregiver said, *I am capable of understanding more people. I have more empathy towards others. I am more sensitive to different styles of communication.* Another caregiver said, *I see people differently. I see people through a more compassionate lens. It's changed my thoughts about what I thought of independence, self-reliance, and self-responsibility. I can now say that some people really are not capable of some of those things without help.*

Participants reported that their overall knowledge base and understanding of mental illnesses and the mental health system has increased. One participant said, *I guess I feel*

fortunate to be able to learn so much about mental health and mental illness. It's definitely

sparked my interest and my passion for mental health. I look at where I volunteer – it's only at

mental health facilities such as drop-in centers. When I am there I feel like I'm at least semi-

educated about [mental health] *so that I can give back in that space.*

One participant spoke about the personal rewards she has experienced from watching her

granddaughter, who struggles with a mental illness, make progress in her mental health recovery.

She said, *She's a very loving little girl and to see her grow from what she was to what she is now*

is tremendous. It's great. Seeing that growth has made a big difference in my life.

A caregiver spoke about a sense of personal growth she has felt as a result of her

experience as a family caregiver. She said,

> *I've learned a lot about myself. So in some ways it's been a wonderful personal growth*
> *experience. You have to be strong enough to take the step of bringing someone to a*
> *mental health facility or to a psychiatrist. I never thought that I would bring a son, a*
> *child, to an acute psychiatric emergency room. And I thought, if I can do that, I can do*
> *anything.*

Challenges and Burden

All participants identified that they experienced some burden in their life due to their role

as a caregiver for their family member with a mental illness.   Challenging areas to note

included: the process of negotiating the relationship with their family member who struggled

with chronic mental illness, not having the depth of information needed to serve effectively in

their role as caregiver, the process of having to revise and recreate the dream they had for their

family member, and time strain.

Negotiating the relationship

All participants identified that they experienced some burden in their life due to their role

as a caregiver for their family member with a mental illness. One participant spoke about the

difficulty of negotiating her relationship with her family member who struggled with a chronic mental illness. She said, *I have found my family member difficult to be around when dealing with depressive symptoms, because they can be really low in energy and not seem like they're willing to put out any effort to be in the relationship or to communicate and take care of their side of things. It was hard to be leaned on so hard for long periods of time when they were extremely difficult to be around.*

Another caregiver spoke about experiencing stress, worry, and sadness due to his son's mental illness. He said, *I have felt excessive stress and sadness from all of this. It's just always on your mind. Wondering what's going to happen next, what will happen when we're not around, or when we're not able to care for him.*

Another participant discussed how serving as primary caregiver to her mother who struggles with schizophrenia has been taxing on her other relationships in her life. She said, *It's exhausting. My husband would say that too, and he's come a long way! It's definitely draining on your relationships.* The participant went on to speak about how her mother's illness has impacted her own family. She said, *I don't really want to have a lot of kids because my mom is kind of like a big grown-up kid. Her illness has impacted my decision making in that part of my life. Plus,* [there's] *the whole concept of the genetic link to mental illness. I think about that when I think about having children of my own. It impacts my decision in that regard.*

Lack of knowledge

One participant noted that her initial lack of knowledge made navigating her role as caregiver to her family member very challenging. She said, *I guess a lot of it for me was not understanding what the heck was going on and why things were the way they were. I couldn't make sense of them. I didn't have the words, the vocabulary, the mental health knowledge that's*

out there to help me. Another participant agreed that the day-to-day interactions with a family

member who has a mental illness can be difficult to manage. She said, *It is very emotionally*

taxing visiting people in the psych ward and having to deal with some of the things that they do

and say.

Another participant spoke about the burden experienced from not knowing what to do to

serve effectively in her role as caregiver to her family member. She said, *The uncertainty and*

the question of, "Am I doing the right thing?" There are so many pieces to the puzzle. Not

knowing which piece is more important or what to do next. Not knowing if you're doing the

right thing is a huge emotional strain. A daughter providing care for her mother who has a

chronic mental illness, reiterated the difficulty associated with making decisions regarding her

mother's care. She said,

> *It's hard to know that her care…changes day to day. People joke, "How do you handle*
> *your mom?" And I'm like, "Every day is different…" You don't know what you're going*
> *to get. So I think that's been the hard part. That forward planning, finding the right*
> *connection points, the constant transition. Just keeping up with all of that. And one little*
> *slip up can really really impact how* [receive benefits].

Several participants noted that stigma plays a notable role in their experience as a family

caregiver to someone with a mental illness. One participant said,

> *The stigma of it is still really bad. And everybody contributes to the stigma now. The*
> *stigma of it is hard to get past and the words we all use are hard to get past. When*
> *people call somebody crazy…That's not a good thing to do. It's just not.*

Another participant said, *It is stigmatized everywhere. Everybody was trying to figure out,*

"Did you cause this?" And they don't understand that mental illness is not caused by the family.

Recreating and revising dreams.

One caregiver spoke about having to re-create her dream for her child who was diagnosed

with a chronic mental illness. She said,

I think the biggest burden or challenge is letting go of this dream that you have that your child is going to be independent from you. I think that's the biggest burden. When you have a child that is so smart… he was like a dream child. He was funny. He was smart. He had never gotten in trouble in school. He was in sports. I mean, everything you would want in a child, really. And he got into the U for chemical engineering. And then when they decompensate from their illness, they can't even fit two normal thoughts together. You think to yourself, how are you going to get this kid back to school so he can get a degree so he can get a job and leave? And then it doesn't happen… So, you go from waiting for the kid to get married and have kids and get a job so you can brag to your friends and pretty soon you're like, well, he's not in jail and he's not in the psych ward. And it's a huge accomplishment! Our son, we just thought he would out shine the rest of them. You know, his personality combined with everything else. So…(Long pause) That takes a long time to get away from.

Time

Four of the five participants spoke about difficulties associated with not having enough time to engage in tasks they might like to – either for themselves personally or to assist in the care of their family member with a chronic mental illness. One participant said, *Being a family caregiver is very time consuming. I don't know what people do if they have a job where they don't have access to the phone during the day.* Another participant agreed, stating,

The most difficult part about serving in my role is the time. I spend many, many hours a week driving and being at appointments. [My family member with chronic mental illness] is always on my mind. And I get calls at work saying I have to leave to go pick her up. The time challenges are hard. It's about making sure that you have enough time, not only for them, but for your friends and your family - the rest of your family. And yourself. Just kind of balancing it. It's a big balancing act.

Participants also identified time as a common barrier that inhibited their ability to seek services to assist them in their role as a family caregiver. One participant said, *I don't have time to go to support groups.* A daughter caring for her mother with a chronic mental illness said, *It would be helpful if there was an in-and-out support. Something that's a little more time efficient. Something that's faster and less time consuming. You want to attend* to [your role as a family caregiver]*, but you don't want to blow all of your energy on that.*

Services

All participants were asked to rate the relevance of a variety of needs related to diagnosis, treatment, medications, and forms of support. Participants unanimously identified all of needs presented as very relevant to their personal situations. Participants identified services, both formal and informal, that assisted them in serving effectively in their role. Participants identified the critical role that social support and case management services play in their ability to engage in family caregiving.

All participants were able to identify sources of support that assisted them in serving more effectively in their role as a family caregiver. Participants highlighted the critical nature of having social support and the impact of case management services. Participants spoke about the impact that their participation in NAMI's Family-to-Family Program had on them, as well as other services which assisted them. Participants also identified gaps in services and provided suggestions for how to improve service delivery.

Social support

Participants were asked to rank the importance of having social support on a scale of 1 to 5, with 5 being very relevant and 1 being not at all relevant to their current needs in their role of family caregiver. Four of the five participants ranked social support as a 5 on the provided scale regarding the extent of relevance to their own needs. The other participant ranked it as a 4. This shows that the perceived need for social support among family caregivers of people with a chronic mental illness is notable.

All participants emphasized the benefits associated with having social support to assist them in their role and provide empathy and encouragement as needed. One participant said,

> *Just knowing that I wasn't the only one dealing with the same thing was so important. Knowing that there were other people out there like me. In support group settings it was*

very enlightening to talk to people and bounce ideas off of them. And it made me a stronger person when I went to advocate for [my family member with a chronic mental illness] because then I knew that I wasn't just guessing. I had confidence that I knew what I was talking about. The support from others validated what I was going through, but it also validated my confidence. So I could advocate for him and say we need better medication, we need this, we need that. This might work because my group said that it might work!

A mother providing care to her son who struggles with a chronic mental illness agreed with the critical nature of having social support when providing care to a family member with a mental illness. She said, *Often times when a kid has a mental illness you are so isolated. Just isolated. When my sons were diagnosed with mental illness, it was stigmatized everywhere that we went. From extended family to school…The doctor, even the psychiatrist. Social support was so important for me.*

One participant identified that the relationships she formed with other Family-to-Family program participants have served as lasting friendships and members of her personal support system. She said, *We knew their [other group members'] history. And there was just such a comfort in that… and now you have all of these friends that, you know what there story is. And it helped. Even if they don't come to the support group, you know that you can email them and we have all of the permission from each other to stay connected.*

A parent caregiver agreed that the mutual aid received among other NAMI Family-to-Family participants was part of what made his experience with the program such a good one. He said, *I think, not just for me, but for everybody else to have everybody else there. It was incredible. The social support was incredibly helpful.*

One participant noted specific ways that members of her support system were particularly helpful to her in her role as a family caregiver for someone with a chronic mental illness. She said,

The people that are in it with you, your friends from the support group and anybody else, it's good to bounce ideas off of them. But sometimes I need someone to say, "You're over-involved!", "No, that's not working.", "Yes, you're on the right track" That to me would be like a support for me.

The participant who noted that she had not engaged in the Family-to-Family program, spoke about a Crisis Group she engaged in when her mother was nearing her discharge date from the hospital. She identified the value of social support and group work while she was in the midst of dealing with her mother's transition back to the community. She said, *It was nice to talk to people. And again, it was more of a crisis mode. I was looking for housing so I was able to put out my question to the group. They offered me their feedback. I thought that it was nice to get to know the people. That was helpful at that time.*

Case management

Several participants commented on how case management services had assisted them in their role as a family caregiver to someone with a chronic mental illness. A parent caregiver began to cry when speaking about his son's case manager because of the assistance she has provided to him and their family, thus making his role as a family caregiver more manageable. He said,

My stress has gone down considerably since [the case manager] got involved. [The case manager] just took over did everything. (starts to cry) I just don't know how to thank [the case manager] at this point (laughing). She just sat with [my son] and advised him through the whole process. She [the case manager] basically told me early on to more or less just step aside and watch. She said would let me know if she needed my help. And then she just kind of knew the system well enough to help me and my son make a plan and get to where we are now.

One participant who works in the mental health field herself, and who also serves as the primary caregiver to her granddaughter who has a chronic mental illness, noted that her granddaughter's case manager was able to help in ways that she could not have done on her own.

She said, *Even though I know a lot of the supports out there, her case manager can access them a lot faster.*

A parent caregiver noted how much more challenging her work in her role as a family caregiver has been since her son who has a chronic mental illness lost access to his case management services. This participant explained that because her son was doing so well and because she was providing so much care for her son on her own, his case management services were terminated by the county. She said,

> *He kind of fell through the cracks. He wasn't bad enough. It was like as soon as he got a job and got some of his court dates out of the way, they were like "Whoa! You're a star pupil!" And I was like, no he's not! I need someone that I could call. Like right now, I've got a problem with the county. We're trying to get [my son with a mental illness] a Rule 25 so that he can go to treatment. He has insurance, but his insurance doesn't cover the treatment. So, just the amount of times you're on the phone asking for help. It would be nice if I had someone to help me navigate this all again.*

Another participant reiterated the concern she had regarding her family member's case management services being terminated. She said,

> *Unfortunately, it's very hard to get a mental health case manager for children. And they're still thinking about taking the case management services away because she's doing so well. She's doing so well because of the supports that are in place because of the case manager. It might be tomorrow that her mental health has a break down.*

NAMI's Family-to-Family Program

Four of the five participants interviewed had engaged in NAMI's Family-to-Family Program. Participants overall had very positive feelings about the NAMI Family-to-Family program. One participant said, *I never thought I wanted to go to a support group about anything. But this is wonderful! If people knew how great it was… it really is.* Another participant said, *The written materials, the knowledge of the instructors, the extent of the information… I've been to a lot of seminars and this was the best I've ever experienced. It doesn't make the experience of having someone in your life with mental illness less hard, but it reduces stress.*

One participant noted that the amount of education and general information she received was especially beneficial. She said, *They focus on a different topic every week. It gave you enough information so that either it was enough to say okay, that's all I need right now, or it gave you somewhere to get more information if you needed it.*

Another participant agreed, noting how informative the program was. He said, *The amount of information and the knowledge of the instructors was amazing. If you're more informed you can understand what your loved one is going through and why you're feeling the way you are. Because sometimes it's just too much.*

A parent caregiver noted that the program's honesty about her family member's prognosis was helpful. She said,

> *They were very brutally honest about everything about mental illness. It wasn't like, "Oh, it's going to get better because you're coming here." It was more of, "You're going to get enough information to feel better and have some tools to help you manage". It's not going to go away. There was no quick fix. But it was definitely nice to know that you had somewhere to go for 12 weeks!*

Additional services. Participants were prompted to identify if they had received any additional services to assist them in their role as caregiver to their family member with a chronic mental illness. One participant noted that she tried doing therapy with her family member, but reported that this was not helpful. Two participants shared that they has received some short-term psychiatric care to assist them in managing the stress stemming from what was required of them in their role as caregiver to their family members.

A parent caregiver spoke about how his experience with yoga assisted him in managing the stress he experienced due to his role. He said,

> *The yoga instructor helped me get through this. When all of this was going on, I couldn't do things I used to once enjoy. I couldn't ride my bike. I couldn't practice yoga at home. I couldn't do anything but work, sleep, and eat. And stare at the TV. Yoga helped me get*

through that. I don't think therapy would have even helped me as I was going through all of the stress. Yoga is therapy.

Another participant spoke about being the recipient of a grant to assist her in providing

care for her granddaughter. She said,

She [my family member with mental illness] *does have a grant through the county that funds some PCA* [personal care assistant] *time. And so that gives me time to be myself, without a child who needs me every second of every minute of every day. The grant also gives a little bit of monetary support for the things that she needs. For instance, I can use it for her sensory needs. I can use it for PCA service. I've used it for therapy that MA wouldn't pay for.*

Gaps in service

Participants were asked to identify additional services or interventions that might be

helpful in meeting their needs as caregiver to someone with a chronic mental illness. One

participant said, *It would be super helpful is if there were some kind of brochure or something*

that says: So your loved one has mental illness. Now what? Something to explain how all of the

resources out there fit together. This participant spoke highly about the written materials

provided by NAMI, but noted that they could be improved further.

One participant spoke about how honesty in crisis was critical for her. She said, *When*

somebody really was honest with me and said, "This isn't going to go away anytime soon" – that

was a turning point for me… I realized that I had been in denial worse than my child. There's

hope and there's help. It just takes a while for it to all work together.

A daughter providing care to her mother who is living with a mental illness mentioned

that she would appreciate programming in the mental health system that was targeted to help

family members engage with the person in their family who has a mental illness. The participant

said,

It would be nice if there were drop-in options for me on the weekend somewhere. You know, fun things at mental health drop in centers that I could take her to. That could

kind of empower the family to do more. I would like to be involved, but sometimes I don't know how.

A grandparent caregiver who utilized PCA services to assist her in her role as a family caregiver spoke about improvements that could be made to improve these PCA services. She said, *It would be helpful to have trainings for PCAs to help them work with kids who have mental health issues that are going to exhibit behavior problems more effectively. If PCAs were paid better, that might gather people who have more experience and can really stick with the position, because PCAs for most families are very transitional.* This same participant said it would be helpful if there was more funding through public grants to help provide care for the individual with mental illness within the community, in order to give the family a break from providing care.

Another participant articulated her desire for guidance about how to be involved in her family member's care from the providers themselves. She said,

> *I feel like I overwhelm the people who care for [my family member with a mental illness]. It would be nice to know what kind of involvement is appreciated. What's too much? What's helpful? What's not? I mean, even if it's just a family meeting to kick off every time you change case managers or ILS* [independent living skills] *workers, just so everybody can kind of level-set and get on that same page. Because I feel like I come in like, "She needs to go to the gym once a week. She needs this and this and this." And I come in with like, my management and all of these past experiences with different psychiatrists. I've got all of this, these examples and I don't know what's helpful or useful. Some guidance in that regard would be helpful.*

Discussion

The purpose of this study was to gain insight into the needs of family caregivers for people who have a chronic mental illness. These findings are consistent with the assertions found in the literature that family members have indeed acquired the responsibility of caring for their relatives with chronic mental illness since deinstitutionalization (Tabatabaina, 2003; Thompson & Doll, 1982; Goodman, 2004). This section will review how this study's findings

compared to literature regarding the impact of deinstitutionalization on families, benefits and challenges of family caregiving, and services targeted at family caregivers. Implications for practice, policy, and future research will also be discussed.

Impact of deinstitutionalization on families.

All participants in this study readily identified themselves as caregivers to their family member who was diagnosed with a chronic mental illness. These individuals expressed beliefs that without their involvement in the care of their family member, they would not be adequately cared for. These findings are congruent with Cummings & MacNeil's (2008) research that showed family care and support to be an essential element in the efficacy of community-based mental health care. These findings are consistent with findings from studies by Anderson and Lynch (1984) and Aschbrenner et al. (2011), noting that family caregivers dedicated notable amounts of energy and resources towards the care of their family member with a chronic mental illness.

In this study, family members of people with chronic mental illnesses did not suggest, as previous literature has, that they were opposed to deinstitutionalization, as noted in Tabatainia (2003). None of the participants in this study expressed their preference that their family member be maintained in a more institutionalized setting. Participants seemed understanding, if not pleased, that their family could exist within the context of the general community.

Benefits

This study confirmed that family caregivers experience some benefits due to their role. Study participants spoke about feeling an increased sense of knowledge about mental illness, a heightened sense of compassion for others, as well as a personal sense of accomplishment. This is consistent with literature that identified that family caregivers "often" had positive interactions

with their family member with a chronic mental illness. More specifically, the researcher found that some family caregivers derived personal satisfaction from their role (Cummings & MacNeil, 2008).

Challenges and burden

All participants in this study identified feeling a sense of burden due to their role as family caregiver to their relative with a chronic mental illness. This finding is consistent with research by Thompson and Doll (1982) that identified 73% of families who have a relative with a mental illness reported being adversely affected in one or more ways due to the care provided (Thompson & Doll, 1982). Participants in this study endorsed experiencing both objective burdens, such as disruption in family functioning and time strains, and subjective burden, such as emotional distress, due to their role in their family member's life. This is consistent with literature that identified the prevalence of these two types of burden (Goodman, 2004; Thompson & Doll, 1982; Cummings & MacNeil, 2008; Ferris & Marshall, 1987; Marley, 1992).

Participants in this study frequently spoke about their experience of not having enough factual information about mental illnesses and the mental health system in order to serve effectively in their role as a family caregiver. This is consistent with Tabatabainia's (2003) research that indicated family caregivers often experience feelings of confusion and lack the knowledge about how to successfully integrate their relative into the community.

Researchers have noted that caring for an individual with a chronic mental illness requires a financial commitment (Goodman, 2004; Morell, 1979; Segal, 1979; Thompson & Doll, 1982; Lai & Thomson, 2011). Only one of the five participants in this study spoke about feeling a financial burden due to their role as a family caregiver. This suggests that public benefits, that many participants noted were being received by their relative, were providing support. It is also

possible that study participants felt that this was something more personal in nature and thus, did not disclose information to the researcher.

Services

This study showed that family members have successfully pursued and engaged with resources to promote their ability to serve effectively in their role. Recreational activities, psychotherapy, and state-funded grants were all noted by participants as services utilized to assist them. This is not necessarily consent with research that indicated that there are minimal services available to meet the needs of families caring for a relative with a chronic mental illness (Cummings & MacNeil, 2008; Morell, 1979).

Participants unanimously agreed that interactional interventions, such as mutual help and other support groups, were helpful in the promotion of their ability to serve effectively as a family caregiver. Participants reiterated the critical role that social support has played in their lives. This is consistent with the literature which indicates the multi-faceted benefits of engagement in interactional interventions (Anderson & Lynch, 1984; Walsh, 1988; Hatfield, 1981; Ferris & Marshall, 1987; Goodman, 2004; Dreier & Lewis, 1991; Cook, Heller, & Pickett-Schenk, 1999).

Participants reported experiencing benefits from their engagement in educational interventions, such as learning new strategies to assist their family member with a chronic mental illness, becoming aware of coping skills to promote their own wellness, and growing their own knowledge base about mental health related issues. This literature also identified the critical nature of educational interventions in order to provide family caregivers with necessary support to serve effectively in their role (Ferris & Marshall, 1987; Tabatabainia, 2003; Goodman, 2004; Dreier & Lewis, 1991; Solomon et al., 1997).

The National Alliance on Mental Illness' Family-to-Family Program, one of the more common educational interventions available for caregivers of individuals with chronic mental illnesses, was spoken of very highly by participants. Four of the five participants in this study had engaged in the Family-to-Family Program. They all described it as a positive experience where they gained supports and insight into how to serve more effectively in their role as a family caregiver. This is consistent with a study by Dixon et al. (2011) which evaluated the effectiveness of the NAMI Family-to-Family program and similarly, found that participants experienced notable benefits from their engagement. This study also supports Cook et al.'s (2009) research, which asserted that family members experienced decreased levels of caregiver burden following their engagement in the NAMI Family-to-Family Program.

Several research participants spoke about the dramatic impact that case management services have had on their experience as a family caregiver and on their relative with a chronic mental illness. This parallels research by Tabatabainia (2003) and Ferris & Marshall which noted that family caregivers face great challenges due to their role and require support in order to adequately engage in caregiving tasks.

Implications for Practice

This section will discuss implications for social work practice, addressing how social workers can affect change in order to better support family caregivers. Specifically, this section will review the need for social workers to utilize group work as a vehicle for serving family caregivers, the importance of providing family caregivers with practical knowledge and facts about mental illness and the mental health system, and suggestions for new and enhanced programming to serve family caregivers more effectively.

Clinical social workers, as well as other mental health workers and helping professionals, can use the information from this study to better understand how to work with family members of people who have a chronic mental illness. They may be better able to identify the needs and available supports available to assist this population in serving effectively in their roles. The information from this study can also be used to create a deeper connection with family members in order to utilize their alliance in the treatment process when serving an individual who has a mental illness. This study also highlights the specific needs of individuals who have a loved one in their life with a mental illness. Social workers can use the information from this study to expand their understanding of these needs in order to create and promote programming directed specifically at this target population.

All participants identified that group work has been critical in their feeling of being supported as a family caregiver to someone with a chronic mental illness. Participants unanimously identified a variety of benefits derived from engaging in group work. Both educational and crisis groups were utilized by participants. The impact that these groups had on participants suggests that social workers should continue to emphasize the use of groups as a vehicle for providing services to family caregivers of individuals with chronic mental illnesses.

Several participants also noted that after having learned practical knowledge and facts about mental illness and the mental health system, they felt notably more empowered and able to serve effectively in their role as a family caregiver. Social workers must ensure that family caregivers receive necessary education about their relative's illness and the mental health system in order to allow for family caregivers to serve effectively in their role. Social workers can create education materials or initiate programs within the context of their own agency to ensure that this need for practical knowledge and facts is being met. It is also important that social

workers maintain an awareness that use of professional jargon with family caregivers could serve as a barrier to effective communication if the caregiver has not received the necessary educational resources.

One participant noted that it would be helpful if there were community programming that provided an opportunity to interact and spend time with her family member with a chronic mental illness. Social workers can help create and implement programming that facilitates healthy interactions between family members and their relative who has a chronic mental illness.

It is important that there is supportive family programming for family caregiver, which takes into account the minimal amounts of time that family caregivers have for extra activities. All research participants spoke about experiencing time strain due to their role. Social workers must take this into account as they develop new programming and enhance current programming targeted to serve family caregivers.

One participant noted the value of mindfulness practice in his ability to serve effectively in his role as a family caregiver. Social workers can provide education and skills training on mindfulness strategies when working with family caregivers. It is possible that independent use of mindfulness techniques could benefit family caregivers and assist them in serving more effectively in their role.

Implications for Policy

This section will detail implications for policy derived from this study. It will review the importance of advocating on behalf of public grants to provide support to family caregivers, assisting family caregivers in becoming involved in the legislative process, and combatting stigma surrounding mental health.

Community-based mental health care has allowed large amounts of money to be used in ways other than funding long-term hospital stays for people with chronic mental illness. Because of family caregivers, individuals with chronic mental illnesses are able to live safely in the community. This study shows that family caregivers also require support. Public funding should be dedicated to address their needs in order to ensure that community-based mental health care is a viable, long-term option for the future.

Social workers can facilitate connections between family caregivers and the legislative process. The voices of family members should be considered as changes to the mental health system are being made. Social workers can help family members engage in the legislative process by providing education and resources to help build connections between family caregivers and their representatives.

Several participants spoke about the impact that the stigma of mental illness has had on them. Through advocacy work at a variety of levels, social workers can continue to aid in reducing stigma surrounding mental illness. Social workers are also in a position where they can empower family caregivers, as well as other professionals in the mental health system, to do the same.

Implications for Research

Further research is necessary to validate the efficacy of specific interventions for family members of people with a chronic mental illness. Program evaluations would also be beneficial in order to determine specific strengths and limitations of different programming options for family caregivers of someone with a chronic mental illness.

With funding for social services decreasing, family-led or peer-led support services will likely be a viable option for effective service delivery for various populations, particularly for

family members of people with a chronic mental illness. Further research that explores the benefits and costs associated with peer-support services would be beneficial.

One participant identified that financial constraints have limited her ability to serve effectively in her role as a family caregiver. The researcher did not ask questions about this. Finances would be an area to address in future research.

Strengths and Limitations

The choice to use a qualitative research modality to explore the research is a strength. Relying on participants' own words, the researcher was able to gain more detailed and in-depth information about their experiences. Because the interviews were done in person, the researcher was also able to observe non-verbal behaviors to assist in eliciting appropriate clarifying questions or follow-up prompts.

Sample size and limited diversity in gender, age, race, and ethnicity affected the scope of the study findings. Future research using a larger and more diverse sample will enrich our understanding of the needs and contributions of family caregivers.

<div align="center">

Conclusion

</div>

Social workers who have an opportunity to work with or alongside family members of an individual with a chronic mental illness can empower family caregivers to serve more effectively in their role. This can be done by assisting them in identifying benefits associated with their role, as well as identifying resources for family caregivers to get their needs met in order to serve effectively in their role. Family members may not have access to the knowledge or resources to do this independently and may require the assistance of social workers in order to assist in accessing or providing these critical services.

This study is consistent with previous research indicating that there are some benefits associated with serving as a caregiver to a family member who has a chronic mental illness. In addition, this study confirms that the burdens associated with having a family member with a chronic mental illness can be difficult to manage independently and reinforces the importance of having a variety of support systems and programs to assist family caregivers in their critical roles.

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History of Mental Health Treatment

Roberts and Kurtz (1987) reported that the major reform movement that is viewed as the first effort to provide humane care to individuals with mental illness is referred to as "moral treatment". This reform movement took place in the early 18th century. As presented by Day (2006), Dr. Philippe Pinel, a French doctor, initiated the reform of the Bicetre Hospital in Paris from a repressive institution into a psychiatrically-oriented and progressive hospital. Pinel believed that people with a mental illness could achieve wellness with treatments including regular exercise, occupational therapy, proper nutrition, and a comfortable environment. William Tuke, a layman from England, is known for playing a role similar to Pinel's in the country of England. He founded a therapeutic retreat for individuals with mental illnesses at York in Northern England in 1796 (Roberts & Kurtz, 1987; Day, 2006).

Dr. Benjamin Rush, who Day (2006) referred to as the father of American psychiatry, introduced the concept of moral treatment at Pennsylvania State Hospital in Philadelphia in 1783. Roberts and Kurtz (1987) asserted that Pennsylvania State Hospital was the first American hospital that focused on providing moral treatment to individuals with chronic mental illness. By 1847 there were 30 asylums along the East coast that were dedicated to this same moral treatment (Roberts & Kurtz, 1987; Day, 2006).

According to Roberts & Kurtz (1987), the first American state hospital, which was created exclusively for the purpose of caring for individuals with a mental illness, was established in 1773 in Williamsburg, Virginia. It took 50 years for similar institutions to be created. In 1822 Kentucky opened a state mental asylum for individuals in poverty and those

who had mental illnesses. Worcester State Hospital in Massachusetts was opened in 1833. Nine

new public hospitals were opened between 1836 and 1842 (Roberts & Kurtz, 1987, Day, 2006).

According to Day (2006), in 1840 Dorothea Dix, a Sunday school teacher from New

England, began her advocacy efforts hoping to establish more mental hospitals across the United

States. She prompted political leaders to initiate legislation mandating the creation of mental

hospitals. In 1848 Dix submitted a proposal to Congress advocating for the reservation of land

to be used specifically for the care of individuals with mental illnesses. This bill, which became

known as the Ten-Million-Acre-Bill mandated that proceeds from federal land sales go towards

the building of public mental hospitals. Although the bill was passed by Congress, it was

promptly vetoed by President Pierce who did not believe that the care for individuals with mental

illness was under the jurisdiction of the federal government (Roberts & Kurtz, 1987; Day, 2006).

By 1850 mental asylums had transformed into large hospitals. The rapid growth of the

immigrant community and impoverished groups of people led to the expansion of the capacity in

asylums. Institutions continued to grow and were soon overfilled (Roberts & Kurtz, 1987).

Roberts & Kurtz (1987) attribute the emergency of the mental hygiene movement to

Clifford Beers, another advocate for the humane treatment of individuals with mental illness and

someone who struggled with a mental illness himself. Beers organized the National Committee

for Mental Hygiene (NCMH) in 1909. The board of the National Committee was made up of

psychiatrists, public health officials, medical personnel, politicians, and community members.

Beers encouraged individual states to establish their own mental health associations in order to

advocate for the elimination of abuse that was believed to be taking place in mental asylums

(Roberts & Kurtz, 1987).

Day (2006) identified that at this time the National Committee for Mental Hygiene (NCMH) began to explore additional concerns relating to mental hospital reform. The expanded mental hygiene movement focused on training mental health professionals, preventative mental health treatment, and bringing attention to the role of mental hygiene in the areas criminal justice, education, and financial matters (Day, 2006).

Deinstitutionalization. The Community Mental Health Movement was marked by the emergence of community based treatment models for individuals with a chronic mental illness (Day, 2006). Home-care services and outpatient clinics became available (Talbott, 1979).

The National Mental Health Act of 1946 (U.S. Congress, 1946) was the first legislation in the mental health arena. It was initiated in response to meeting the mental health needs for veterans returning from combat (Talbott, 1979). It authorized funds to: (1) Foster and aid research related to the cause, diagnosis, and treatment of neuropsychiatric disorders; (2) Provide for the training of personnel; (3) Provide opportunities for the award of fellowships to individuals working in the mental health field; (4) Provide opportunities for grants to public and nonprofit institutions, and (4) Aid states in the prevention, diagnosis, and treatment of neuropsychiatric disorders through grants and technical assistance (U.S. Congress, 1946; Day, 2006).

The Mental Health Study Act of 1955 authorized the creation of the Joint Commission on Mental Illness and Health (Roberts & Kurtz, 1987; U.S. Congress, 1955). Congress subsequently endorsed funds for the Joint Commission to conduct a study exploring the approaches to treatment for mental illness across the country. The Joint Commission sought to articulate recommendations for improving the care and treatment for individuals with mental illnesses. The final report, "Action for Mental Health", was published in 1961. It advocated

strongly for the enhancement of the current system of providing care to persons with mental

illnesses (Roberts & Kurtz, 1987).

ⓦ nami
National Alliance on Mental Illness
MINNESOTA

October 30, 2011

Dr. Carol Kuechler
Clinical Research Committee Chair
St. Catherine University/University of St. Thomas
School of Social Work

Dear Dr. Kuechler:

I am writing this letter to formally acknowledge NAMI Minnesota's support of Emily Ross' clinical research project: In Their Own Words: Needs and Services for Families of Individuals with Chronic Mental Illness.

NAMI will distribute the flyer to all of our Family-to-Family class participants in order to recruit potential research participants. They will then have the option of calling her in order to participate in individual, face-to-face interviews. Ms. Ross will use these interviews to gain insight into the needs of family members of individuals with chronic mental illness and how their engagement in NAMI's Family-to-Family program has assisted them in fulfilling these needs.

I understand that Ms. Ross' procedure to maintain our class participants' confidentiality and safety will include a participant consent form (which will be distributed and reviewed prior to the beginning of all interviews). I understand that Ms. Ross will keep forms in a locked file which only she has access to. I acknowledge that all audio-taped interviews and interview transcriptions will be stored on a personal computer with a password in order to ensure confidentiality of all research participants. I recognize that Ms. Ross will destroy this information by May 14th, 2012, upon the completion of this research project. In any publically published or presented context, only anonymous data will be reported.

I understand that this study will not proceed until it has been approved by the St. Catherine University's Institutional Review Board. It is anticipated that Ms. Ross will conduct her interviews during January 2012. I am aware that this research is part of Ms. Ross' clinical research paper, which will be published and presented to the public in May of 2012. All reports of this research will be conducted in a way that protects the confidentiality of all participants.

Sincerely,

[signature]

Sue Abderholden, MPH
Executive Director

⚕Community
Health Charities
MINNESOTA

800 Transfer Road, Suite 31, St. Paul, MN 55114
651-645-2948 or 1-888-NAMI-HELPS   www.namihelps.org

Do you care for a person
with a chronic mental illness?
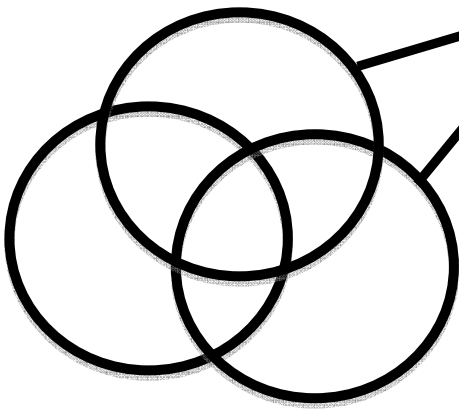
Are you interested in being part of a study that explores how to better support family members and others who care for and about individuals with a mental illness?

If so, **you are invited to participate in a study!**

The purpose of this study is to explore the needs of individuals - like you - who care about a person with a chronic mental illness and to identify ways in which you use supports to assist you in managing your role.

Interested in participating?
Please contact Emily Ross to schedule a 45-60 minute individual interview
eeross@stthomas.edu
(952) 212-8436
This study will be conducted by Emily Ross, BSW, LSW – a student in the St. Catherine University/University of St. Thomas Master of Social Work Program

IN THEIR OWN VOICE: NEEDS OF THOSE WHO CARE FOR INDIVIDUALS WITH CHRONIC MENTAL ILLNESSES

CONSENT FORM

Introduction:
This study will be exploring the needs of people who care for someone with a chronic mental illness. I invite you to participate in this research. You were selected as a possible participant because you have engaged in the National Alliance on Mental Illness' Family-to-Family Program or another form of support targeted at this population. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Emily Ross, graduate student at the School of Social Work under the advisement of Dr. Carol Kuechler, a professor at the school.

Background Information:
The purpose of this study is to explore the needs of individuals who care for someone with a chronic mental illness and to identify ways in which they use supports such as the National Alliance on Mental Illness' Family-to-Family Program to assist them. This information will be shared with social workers to help them understand the needs of those who care for individuals with mental illnesses.

Procedures:
If you agree to be in this study, the researcher will ask you to complete an audio-taped interview that will last approximately one hour. The interview questions will address some basic demographics as well as your experience, needs, and supports used in order to assist you in your role as someone who cares for a person with a chronic mental illness. The interview will be held in a private place that is mutually agreed upon. You will be given a copy of the consent form along with a list of resources to assist you if you have any questions or concerns after the interview.

Risks and Benefits of Being in the Study:
The study has minimal risks. Talking about your role as someone who cares for a person with chronic mental illness may be uncomfortable. If this happens, you may skip any questions you do not feel comfortable answering and may stop the interview at any time without penalty. If you decide to stop the interview prior to the completion you will be asked if you would like the data used in the research study. If you do not want it used the data will be destroyed. You may skip any question that you do not want to answer. A list of resources will be provided at the beginning of the interview in the event you need more assistance in dealing with any emotions

that were experienced during the interview. There are no direct benefits to your participation in this study.

Confidentiality:
The records of this study will be kept confidential. When transcribed, the text will not include any names and in any published report, no identifying information will be included. All forms will be kept in a locked file in the researcher's home that only the researcher has access to. All audio-recorded interviews and interview transcriptions will be kept on the researcher's personal computer, which requires secure password access. Only the researcher will have access to the original records. The audio-tapes and transcriptions will be used for educational purposes only and destroyed after all data is collected and analyzed on or before June 1, 2012.

Voluntary Nature of the Study:
Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relations with the National Alliance on Mental Illness, St. Catherine University, University of St. Thomas, or the researcher.

Contacts and Questions
If you have any questions, please feel free to contact the researcher, Emily Ross. You may ask questions now, or if you have any additional questions later, the faculty advisor, Carol Kuechler (651-690-6719), will be happy to answer them. If you have any other questions or concerns regarding the study and would like to talk to someone other than the researcher, you may also contact John Schmitt, PhD, Chair of the St. Catherine University Institutional Review Board, as (651) 690-7739.

You will be given a copy of this form to keep for your records.

Statement of Consent:
You are making a decision whether or not to participate. Your signature indicates that you have read this information and your questions have been answered. Even after signing this form, please know that you may withdraw from the study at any time and no further data will be collected.

I consent to participate in the study and I agree to have my interview with the researcher audio-recorded.

_____   _____

Signature of Study Participant   **Date**

_____

Print Name of Study Participant

_____   _____

Signature of Researcher   **Date**

Appendix E

Research Questions

Assurance of Participant Understanding
How would you describe the purpose of the study?
What will I be asking you to do as part of this study?
What can you do if you feel uncomfortable with a question that I ask you?
_____
1. How would you describe your role in the life of the person you care for or care about who has a mental illness? (e.g. Interested family member? Primary caregiver? Someone who supports other members of the family?)

2. How long have you been in this role?

3. What benefits, if any, have you received/felt due to your role?

4. What challenges/burdens, if any, have you encountered/felt due to your role?

5. How, if at all, have you been involved in this person's treatment?

6. On a scale of 1 to 5 (5 being the most, and 1 being the least), how satisfied are you with your level of involvement in the treatment of the person you care for or care about?

Not Satisfied   Very Satisfied
1   2   3   4   5

7. Researchers who work in the area of mental health have identified common needs and areas of interest for people who care about or care for individuals with chronic mental illnesses. Using this list (Give Appendix F to participant), I am going to ask you about these needs and areas of interest. On a scale of 1 to 5 (5 being very relevant and 1 being not at all relevant), how important are each of the following needs to you?

Current information on various mental illnesses
1   2   3   4   5
Not at all relevant   Very relevant

Up-to-date information about medications
1   2   3   4   5
Not at all relevant   Very relevant

Up-to-date information about medication side effects
1   2   3   4   5
Not at all relevant   Very relevant

Strategies about medication adherence
1   2   3   4   5
Not at all relevant   Very relevant

Information on evidence-based, most effective treatments for mental illness
1   2   3   4   5

Not at all relevant   Very relevant

Information to assist in understanding the subjective, lived experience of a person with mental illness
1   2   3   4   5
Not at all relevant   Very relevant

Social Support
1   2   3   4   5
Not at all relevant   Very relevant

Techniques for problem solving, listening, and communication skills
1   2   3   4   5
Not at all relevant   Very relevant

Crisis intervention strategies
1   2   3   4   5
Not at all relevant   Very relevant

Relapses prevention techniques
1   2   3   4   5
Not at all relevant   Very relevant

Information on caregiver burnout
1   2   3   4   5
Not at all relevant   Very relevant

Guidance on locating appropriate supports and services within one's community
1   2   3   4   5
Not at all relevant   Very relevant

Information on advocacy initiatives designed to improve and expand services for individuals with mental illness
1   2   3   4   5
Not at all relevant   Very relevant

Now we are going to talk about your experience with the NAMI Family-to-Family program (if applicable) and other ways in which you have been able to get your needs met.

8. How did you learn about NAMI's Family-to-Family Program?

9. Have you completed NAMI's Family-to-Family Program?
If yes, when did you complete the program?
If no, how far along are you in the program?

10. Has NAMI's Family-to-Family program addressed some of the needs you brought up? If so, how?

11. What, if any, other services have you received to support you in your role?

12. What needs, if any, do you have related to your current role that are currently unmet? Tell me about these.

13. What would be helpful to meet these needs?

14. Is there anything else you want to say?

Appendix F

Interview Guide

	1	2	3	4	5
	1	2	3	4	5
Current information on various mental illnesses	1	2	3	4	5
Up-to-date information about medications	1	2	3	4	5
Up-to-date information about medication side effects	1	2	3	4	5
Strategies for medication adherence					
Information on evidence-based, most effective treatments for mental illness	1	2	3	4	5
	1	2	3	4	5
Information to assist in understanding the subjective, lived experience of a person with a mental illness	1	2	3	4	5
Social support	1	2	3	4	5
Techniques for problems solving, listening, and communication skills	1	2	3	4	5
	1	2	3	4	5
Crisis intervention strategies					
Relapse prevention techniques	1	2	3	4	5
Information on caregiver burnout					
Guidance on location appropriate supports and services within one's community					
Information on advocacy initiatives designed to improve and expand services for individuals with mental illness					

Not at all
relevant   Very Relevant

1   2   3   4   5

Resource List

Below are a list of agencies and other resources that can assist you in addressing any needs you might have following the interview.

Interprofessional Center for Counseling and Legal Services
Counseling Services and Social Work Services
Interprofessional Center for Counseling and Legal Services
1128 Harmon Place, Suite 100
Minneapolis, MN 55403

Phone: 651-962-4820
Fax: 651-962-4815

Crisis Connection
Phone: 612-379-6363

National Alliance on Mental Illness- MN Chapter
651-645-2948