Chronic Manic Depressives, Schizoaffectives and their Female Family Caregivers:

The Political Economy of Mental Health Care and the Governance of Madness

by

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ABSTRACT

This study uses a feminist political economy framework and Foucault's (1991:102) notion of "governance" to examine 1) problems, issues and tensions created for 15 women as primary family caregivers of 17 chronically mentally ill family members and 2) governance by these women of their family members, and 3) resistance of their family members. The subjects reported a never-ending burden of caregiving, domestic and wage labour coupled with social isolation, stressed interpersonal relationships and stigma. Caregiving was fraught with crises and uncertainties including: abuse of the family member and caregiver, alcohol and drug abuse by the family member and the potential danger to themselves and/or others. Caregivers exercise skill and governance of family members through monitoring and controlling: manic and depressive episodes, medical compliance, outpatient hospital treatment, hospitalization, medical file information with reported resistance by family members. The study concludes with recommendations for reforms, innovations and suggestions for further research.

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This work is grounded in and owes its existence first and foremost to my family, to the female family caregivers in this study and their care recipients. In the first place I would like to express my gratitude to my father Maher and mother Lilianne for their firm support, trust and endurance whose importance cannot be overstated. I am also very grateful to the women and family members in this study whom I had the honour to meet, and who spiritually effected and enriched me in different stages of my graduate work.

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Finally, for all family caregivers and their loved ones with chronic mental illness who persist in their day to day struggle of living and to the memory of those who have lost the struggle.

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DEDICATION

For Maher Alexander Hanna, my life long teacher, friend and father.

"Get up," the master said, "onto your feet.
The way is long and the road is arduous-
and the sun's already well up in the sky."
Dante's Inferno 1993: Canto XXXIV

1.0 CHAPTER ONE: INTRODUCTION

The provision of mental health care services in Canada, like health care services in general, is a provincial responsibility whereby each province and territory develops its own policy responses relative to its own fiscal circumstances. The procurement of mental health care services has become an increasing challenge for many Canadians faced with chronic mental illness and their family caregivers. The ongoing process of deinstitutionalization,[1] cutbacks to mental health services and expectations of the health promotion framework contribute to these challenges. Further, the conflicting nature of mental health policy directives, the Canadian Charter of Rights and Freedoms, the Uniform Mental Health Act and provincial mental health legislation also contribute to these challenges.

Mental health legislation was originally intended to remedy past abuses and violations of the rights of the mentally ill. However, there are contradictory liberal rights and medical model[2] discourses embedded within and between mental health policy, and the

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[1] The term "deinstitutionalization" will be used in this thesis in a conceptual manner so as to encompass three usages of the term that have evolved in contemporary sociological literature on mental illness and include: rehabilitation of the mentally ill from institutional dependence, removal of patients from hospitals that care for the mentally ill and care systems providing noninstitutional alternatives.

[2] The "medical model" typically employed in clinical practice and research assumes that diseases and mental illness are universal biological or psychophysiological entities, resulting from somatic lesions or dysfunctions (Engel 1994). These produce "signs" or physiological abnormalities that can be measured by clinical and laboratory procedures, as well as "symptoms" or expressions of the experience of distress, communicated as an ordered set of complaints (Engel 1994). The primary tasks of clinical medicine and psychiatry are diagnosis, that is, the interpretation of the patient's symptoms by relating them to their functional and structural sources in the body and to underlying disease entities and rational treatment aimed at intervention in the disease mechanisms (Engel 1994). While the purpose of medical treatment is to alter the structure and functions of the body to influence favorably the course of a physical disease, the purpose of psychiatric treatment is to alter mood, thought and behavior (Leifer 1992). The remedy within the medical model for disability-related problems is cure or normalization of the individual and the agent of remedy is the medical professional (Hanna 1996a:200).

Canadian Charter of Rights and Freedoms, the Uniform Mental Health Act and provincial mental health legislation on the chronically mentally ill. These contradictory liberal rights and medical model discourses reinforce the rights of the mentally ill both to receive and to refuse treatment, and recognize the right to refuse care as more important than the right to care even in situations where intervention is required. They simultaneously reinforce and reject the medical model of madness, and they present a paradox that may exacerbate the challenges that face women in their roles as primary family caregivers of the chronically mentally ill and as state designated mental "health promoters" (Epp 1988:17) for their family members.

Deinstitutionalization and the shift to community care in Canada began as early as the 1960s and 1970s in several provinces with the stated objective of placing as many psychiatric patients as possible in the community[3] (Grier 1992:28, 29). The state's increased efforts at deinstitutionalization have intensified the trend of decreasing mental hospital populations and although more of the mentally ill are remaining in the community, the question increasingly becomes, "[u]nder what conditions?" (Conrad and Schneider 1992:68) Overall, the process of deinstitutionalization has had mixed results. According to researchers Conrad and Schneider (1992:68) and Armstrong and Armstrong (1996:86-88) the process, to date, has had both positive and negative outcomes. More of the mentally ill

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[3] According to Armstrong and Armstrong (1996:86-87), the ongoing process of deinstitutionalization in Canada was justified in the following: new drugs and changing attitudes in the general population allowed people to leave the institutions: the move would allow people to become more independent, to live more dignified lives, and to be better integrated into the community; it was what people wanted and it would save money. The same justifications are being used today to cut back even further on the number of people admitted to long-term psychiatric services and to reduce the numbers of people in extended and rehabilitative care.

are receiving treatment in outpatient facilities, fewer are becoming "institutionalized", a few previously unserved populations are being served and some reforms have taken hold in mental hospitals. Hospitalization of the mentally ill is shorter and the team approach has included more nonpsychiatrists such as occupational therapists in treatment programs. However, there has been no apparent success in preventing mental illness; difficulties have been encountered in the continuity of care of the chronically mentally ill in communities; patients have been "dumped" from mental hospitals without the availability of appropriate alternatives and rehabilitation has been minimal (Conrad and Schneider 1992:68; Armstrong and Armstrong 1996:86-88). Consequently, the caregiving needs of the chronically mentally ill have been neglected. The conditions which ensue impose personal and financial costs on family caregivers, more than likely to be women, the state's mental health and legislative systems to which they turn to for assistance and ultimately on society as a whole.

Although the process of deinstitutionalization in Canada "is described as sending people back to the community", Armstrong and Armstrong (1996:88) maintain that "this community largely exists in the imagination of those justifying the policy. In most cases, back to the community means shifting responsibility to women who do the unpaid caring work in their own homes." Similarly, Waerness (1987:225) argues that "women provide most of the care giving work as unpaid family work and the bulk of the helping that in western societies is reported as community care turns out on closer scrutiny to be care by close female relatives, a point which is seldom clearly stated."

1.1 Objective of Study and Structure of Argument

Despite over thirty years of sociological research on mental illness in the family, little is known about the post-1960s deinstitutionalization experiences of women as primary family caregivers of those with chronic mental illness. Female family caregiving and the rationality involved in caregiving are issues that until recent years have scarcely received any attention in the sociological literature. This has occured even though the concept of rationality has been a central issue in sociology since the time of the founding fathers. What caregiving means for women and how caregiving services are to be carried out in the welfare states of the western world today has, only recently, attracted the interest of sociologists. This interest is, in part, due to the challenges emerging from feminism and the search for a women's perspective in social theory; and, in part, because of the more recent shift in social policy debate dealing with the public services (Waerness 1987:207). This shift toward a belief in community care is spreading rapidly because it is supposed to be less costly and morally preferable to the public caregiving services. However, public policy fails to consider the impact of community care on the lives of women as primary family caregivers of the chronically mentally ill (Waerness 1987:207).

Contemporary sociological research on chronic mental illness has neglected to examine, from a feminist perspective, the consequences of post-1960s deinstitutionalization for female family caregivers. More extensive research is required in that "[c]larifying the specific identity of those most involved with the care of mentally ill adults may have important implications for delivery of mental health services, particularly in how we perceive the families of the mentally ill and how we help them." Further, "[i]t may also direct our attention to their needs and facilitate further study of their long-term stressors and burdens" (Ascher-Svanum and Sobel 1989:843).

The sociological inquiry of how women, as primary family caregivers of the chronically mentally ill, learn how to navigate caregiving relationships and acquire relational intelligence under quite irrational tensions on both macro and micro levels is not at all simple. The study of female family caregiving and the "governance" (Foucault 1991:102) of their chronically mentally ill family members is far more complex than what is often understood of caregiving as micro human connections of patting family members on the head, passive listening or ceaseless production of soothing utterances (Gordon et al. 1996:xiv). As Gordon et al. (1996:xiv) assert "[c]aregiving is extensive as well as intensive work." The use of Foucault's (1991:102) notion of governance as a "very specific albeit complex form of power", used in this thesis, transcends the private sphere understanding of caregiving as emotions and expressiveness; governance offers a broader understanding of the rationality and instrumentality involved in the management of private troubles and public issues facing women as primary family caregivers of the chronically mentally ill.

This qualitative sociological study will examine: 1) the problems, issues and tensions created for 15 women as primary family caregivers of eight chronic manic depressive family members and nine chronic manic depressive family members with schizophrenic tendencies (or schizoaffectives) by macro level deinstitutionalization, cutbacks to mental health services, expectations of the health promotion framework and mental health policy, and the contradictory liberal rights and medical model discourses embedded within and between mental health policy and legislation and 2) the governance by these women of their chronically mentally ill family members to manage the contradictions in their roles as primary family caregivers and as state designated mental health promoters, and the resistance of their chronically mentally ill family members to this governance.

The critical and complex issue of female family caregiver governance of their chronically mentally ill family members remains largely uninvestigated in contemporary sociological literature within the context of a feminist analysis of broader political and economic changes. This thesis is an attempt to help fill in this gap, bridging theory and practice, within a feminist political economy framework and using the notion of governance. Consequently, this thesis makes significant contributions to contemporary sociological literature on mental illness with new theoretical and practical insights into the consequences of post-1960s deinstitutionalization for female family caregivers.

This thesis supports Smith's (1987:99) contention that, as sociologists and feminists "[m]aking the everyday world our problematic instructs us to look for the 'inner' organization generating its ordinary features, its orders and disorders, its contingencies and conditions, and to look for that inner organization in the externalized and abstracted relations of economic processes and of the ruling apparatus in general." Further, feminist sociological inquiry "then can begin from the position of women, in whatever relation determines their experience as it is. It can begin from the position of any member of the society, explicating the problematic of her or his experience as a sociological problematic." As Smith (1987:99) maintains, the implications of a sociology for women in contemporary corporate capitalistic society pose again, though with a different grounding, the problematic originally formulated by Marx and Engels (1973:30) that is "[i]ndividuals always started, and always start, from themselves. Their relations are the relations of their real life. How does it happen that their relations assume an independent existence over against them? And that the forces of their own life overpower them?"

The central argument of this thesis is that deinstitutionalization, cutbacks to mental health services, expectations of the health promotion framework and mental health policy, and the contradictory liberal rights and medical model discourses embedded within and between mental health policy and legislation on a macro level or what I term the "macro caregiving context" has created problems, issues and tensions on a micro level for female family caregivers. Through female family caregiver governance of chronically mentally ill family members, caregivers try to manage these problems, issues and tensions, and the contradictions in their roles as primary family caregivers and as state designated mental health promoters with resistance from these family members.

With a feminist political economy framework and notion of governance in place in this study, several central questions emerge. What are the problems, issues and tensions created for women as primary family caregivers of chronic manic depressives and schizoaffectives by macro level deinstitutionalization, cutbacks to mental health services, expectations of the health promotion framework and mental health policy? What are the problems, issues and tensions created for these women by the contradictory liberal rights and medical model discourses embedded within and between mental health policy and legislation? What is the nature of the governance of chronic manic depressive and schizoaffective family members by these women in managing these problems, issues, tensions, and the contradictions in their roles as primary family caregivers and as state designated mental health promoters? What is the nature of the resistance of these family members to this female family caregiver governance? I will address these questions through a comprehensive analysis of my study findings in this thesis.

1.2 Health and Mental Health Policy

Women as primary family caregivers of the chronically mentally ill are faced with managing the tensions that exist between the expectations of health and mental health policy and the health promotion framework and their liberal rights and medical model discourses. The state's position is that mental health promotion is primarily a "community and private responsibility" (Armstrong and Armstrong 1996:87). In the framework, the state's view of health and mental health is one that "recognizes freedom of choice and emphasizes the role of individuals and communities in defining what health means to them" (Epp 1986:3). Further, in the framework, the state defines mental health as "the capacity of the individual, the group and the environment to interact with one another in ways that promote subjective well-being, the optimal development and the use of mental abilities (cognitive, affective and relational), the achievement of individual and collective goals consistent with justice and the attainment and preservation of conditions of fundamental equality" (Epp 1988:7).

Mental health policy and promotion is clearly centered around medical compliance and the medical model of madness. The state maintains that although little can be done in terms of primary prevention of the onset of mental illness, the prevention of relapse of mental illness can be easily promoted through the management of symptoms that has been facilitated by "pharmacological and other modalities" (Epp 1988:8). Further, according to the state, mental disorders result "from biological, developmental and/or psychosocial factors, and can in principle, at least - be managed using approaches comparable to those applied to physical disease (that is, prevention, diagnosis, treatment and rehabilitation)" (Epp 1988:8). This mental health policy approach and definition is centered around the medical model of madness and dominated by allopathic medicine[4] in which the primary approach is a service delivery system that is "focused on penetration of the body physically by surgery and chemically by drugs" such as psychiatry and medication in the case of the chronically mentally ill (Armstrong and Armstrong 1996:19). Given the health promotion framework's strong emphasis on "community and private responsibility", medical compliance and the medical model of madness, women as primary family caregivers of the chronically mentally ill are expected to assume the responsibility of monitoring their family members for symptoms and medical compliance while ensuring that their basic needs such as food, shelter and clothing are being met.

The health promotion framework (Epp 1986) proposes three health and mental health promotion mechanisms and three implementation strategies that within a mental health context

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[4] For an excellent in-depth, critical discussion of the five central assumptions and challenges to the allopathic approach see Armstrong and Armstrong (1996:20-41).

reflect themes of "community and private responsibility" and the medical model of madness. These three mechanisms are considered to be "intrinsic to health promotion" (Epp 1986:7) and mental health promotion and include: self-care, mutual aid and the creation of healthy environments. The three strategies "or processes whereby we [the state] can act decisively in response to the health challenges confronting Canadians" (Epp 1986:9) include: fostering public participation, strengthening community health-services and co-ordinating healthy public policy. Although the framework links the three micro level mechanisms to the three macro level state strategies, a stronger emphasis is placed on mechanisms for health and mental health promotion. The first mechanism, self-care, is defined as "the decisions and actions individuals take in the interest of their own health" (Epp 1986:7). Self-care, as conceptualised in health promotion policy, refers largely to individual lifestyle decisions and practices specifically for the preservation of health. This mental health promotion mechanism is being left to the initiative of women as primary caregivers who are expected by the framework to assume much responsibility for taking decisions and actions in the interest of the mental health of their chronically mentally ill family members.

The second mechanism, mutual aid, is defined as "the actions people take to help each other cope" (Epp 1986:7). From the mental health promotion perspective, mutual aid is seen as an informal complement to professionally provided care and services available in the formal mental health-care system. However, with the ongoing process of deinstitutionalization and cutbacks to mental health care services it should be pointed out that self-care, mutual aid and the creation of healthy environments as mental health promotion mechanisms may also be seen as alternatives to professional services from the formal mental health-care system (Bolaria 1994). Increasingly, as these mental health promotion mechanisms are seen as less costly and more effective and as alternatives to professionally provided health-care services, female family caregivers of the chronically mentally ill will be expected to assume greater caregiving responsibilities in the name of these mechanisms. The third mechanism, the creation of healthy environments, is defined as 'the creation of conditions and surroundings conducive to health" (Epp 1986:7). This mental health promotion mechanism is being left to the initiative of women as primary caregivers who are expected by the framework to assume much responsibility for creating and maintaining mental health.

The first strategy, fostering public participation, is defined as 'helping people assert control over factors which affect their health" (Epp 1986:9). This is achieved through the two mechanisms of self-help and mutual aid. The second strategy, strengthening community health services, is defined as making 'community services become more active in helping people to cope with disabilities" (Epp 1986:10). The third strategy of co-ordinating healthy public policy is essentially a recognition that since a broad spectrum of policy decisions can and do affect people's behaviours and hence affect health, mental health and illness (such as income security, employment, education, housing, business, agriculture, transportation, justice, and technology), public policy in all realms should be co-ordinated in line with health and mental health promotion (Epp 1986:10).

For the state, there is a clear advantage to an overall emphasis on 'community and private responsibility", medical compliance and the medical model of madness in the framework. First, this overall emphasis is a relatively low cost strategy. Second, the emphasis on private responsibility and personal behavior leaves pharmaceutical companies relatively free of state interference and creates new markets for selling "wonder" medications such as Prozac (Armstrong and Armstrong 1996:43). Third, the emphasis on "community and private responsibility" and personal behavior in the promotion of mental health creates the appearance of government action on mental health promotion while placing the responsibility firmly on the individual and women as primary family caregivers. Fourth, it promotes an ideology of individual responsibility rather than of collective responsibility that serves as a diversion from government inaction (Armstrong and Armstrong 1996:43).

The framework's emphasis on "community and private responsibility", medical compliance and the medical model of madness in the prevention of mental illness has implications for women as primary family caregivers of the chronically mentally ill. First, with this overall emphasis, it is women who are expected by the state to improve the health and mental health practices of not only themselves, but also their family members who may have chronic mental illness (Armstrong and Armstrong 1996:43). Second, the emphasis on "community and private responsibility" blames the victims of what may often be social conditions beyond their control that increases the stress levels on individuals with chronic mental illness and women as their primary family caregivers who may not have the power to change their situation (Armstrong and Armstrong 1996:43). Third, mental health promotion or prevention defined primarily as a "community and private responsibility" does little about the major determinants of mental health in that many of what are defined as personal practices are structured by social and economic circumstance and by working conditions, and are reflected in the inequalities of health status related to class, race, sex, and location (Armstrong and Armstrong 1996:43).

Finally, the framework places significant demands on these women since mental health policy and legislation simultaneously reinforces the rights of their chronically mentally ill family members both to receive and to refuse treatment. Paradoxically, according to the state (Epp 1988:18) "[a]ll Canadians have equal rights to participate in Canadian society, including the right to health and social services, education, employment, housing and recreation, and the right to be protected by the law" however "the first priority must always be to restore the individual as quickly as possible to the full exercise of all rights and responsibilities" (Epp 1988:19). According to current legislation, the chronically mentally ill have been granted the contradictory right to state care and the right to refuse state care. These contradictory rights in addition to the ongoing process of deinstitutionalization and cutbacks to mental health services constrain the nature and extent of care that the state provides to the chronically mentally ill with real costs and consequences for women as their primary family caregivers.

1.3 Mental Health Legislation

The safeguarded contradictory liberal rights of the chronically mentally ill to receive and refuse treatment, among other rights, were granted with the adoption of the Canadian Charter of Rights and Freedoms in 1982. Every provincial and federal law including all mental health legislation must comply with the Charter, which is the supreme law of Canada. If a court finds that a provincial or federal law pertaining to the rights of the mentally ill violates a right under the Charter, that law may be found to be invalid and struck down. Although there are limits placed upon Charter rights, these must be reasonable and justifiable in a free and democratic society. A potentially unconstitutional law will remain valid until it is successfully challenged or until it has been established, in a judicial decision, that the law is in violation of the Charter.

In the context of mental health issues and the rights of the chronically mentally ill, the pertinent sections of the Charter are 7, 9, 12, 15 and 1 (Gaudet 1994:4). For women as primary family caregivers of the chronically mentally ill and the panoply of state agents such as psychiatrists, doctors, social workers and police who are frequently involved in the care and/or management of their symptoms "achieving and maintaining the intricate balance of rights remains an ongoing challenge" (Gaudet 1994:30). Under section 7, an individual cannot be deprived of life, liberty or security of the person unless that deprivation is in accordance with the principles of fundamental justice; under section 9, a person is guaranteed the right not to be arbitrarily detained or imprisoned; under section 12, a person has the right not to be subjected to cruel and unusual treatment or punishment and under section 15, every person is equal under the law and has the right not to be discriminated against on the basis of mental disability (Gaudet 1994:4). Although the Charter guarantees certain rights under the sections mentioned, a qualification under section 1 serves to limit the absolute scope of those guarantees (Gaudet 1994:4). Under section 1, Charter rights are subject to reasonable, justifiable limits and a court may decide that the violation of a right that is guaranteed under the Charter is reasonable and therefore justified in today's society (Gaudet 1994:4). Despite section 1 and its potential to limit the rights of chronically mentally ill individuals who may pose a harm to themselves or others, the Charter primarily strives to safeguard their rights and protect them from involuntary detention and treatment.

These contradictory liberal rights for the chronically mentally ill are also embedded within the 1987 Uniform Mental Health Act that serves as a guide for the legislative incorporation of the requirements of the Charter of Rights and Freedoms into provincial and territorial mental health legislation. The Act was intended to serve as a vehicle for change and the ultimate standardisation of mental health legislative provisions in Canada, related, for example, to treatment and committal (Gaudet 1994:17). The main principles that form the essence of the proposed Uniform Mental Health Act include: 1) a system which promotes voluntary admission and detention, and treatment with informed consent that is preferred to compulsory services 2) where there is no alternative to compulsory services which limit a person's liberty or right to make decisions, these limitations must conform with the Charter 3) a range of appropriate treatment options, including the least restrictive and intrusive alternatives are offered and explained to the person 4) the duty of confidentiality of medical file information is heightened by the vulnerability of a mentally ill person and the potentially severe consequences of improper release of such information 5) the patient has a right to view documents gathered for the purpose of accuracy and 6) if a person's rights and freedoms are affected by legislation, an independent body or a court can review the decision to determine whether or not the decision was reached fairly (Gaudet 1994:18).

Many of the provinces and territories have legislation that conforms with the fundamental principles of the Uniform Mental Health Act. Provincial and territorial mental health legislation in Canada, as with the Charter and the 1987 model Act (Uniform Mental Health Act) reflect contradictory rights and concerns of involuntary admission and detention criteria; informed consent; capacity to consent; substitute consent; compulsory treatment; confidentiality and disclosure of clinical records; and review conditions. The care, treatment and admission to mental health facilities of the 17 family members of the female caregivers participating in this study are governed by provincial mental health legislation in both Ontario and Quebec. All aspects of provincial mental health legislation are of critical importance in determining the extent, nature and duration of care that an individual with chronic mental illness will receive from the state and their female family caregivers.

Provincial and territorial mental health legislation in Canada require a diagnosis of mental disorder as one of the criteria for involuntary admission. Relevant to the concerns of female family caregivers in this study are the legislated definitions of "mental disorder" in Ontario and Quebec in that thirteen women and their family members resided in Ontario and two women and their family members resided in Quebec. While Quebec mental health legislation does not have a legal definition of mental disorder, Ontario defines "mental disorder"[5] vaguely as "any disease or disability of the mind" (Gaudet 1994:19). Given the absent and vague definitions of "mental disorder" in Ontario and Quebec mental health legislation, any attempts by the women in this study to involuntarily admit their chronically mentally ill family members may be challenged and met with resistance and may prove to

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[5] Under the Uniform Mental Health Act, the term "mental disorder" is vaguely defined as "a substantial disorder of thought, mood, perception, orientation or memory that grossly impairs judgement, behaviour, capacity to recognize reality or ability to meet the ordinary demands of life" (Gaudet 1994:19).

be frustrating for these women.

The current common involuntary admission practice in Canada is to have one physician complete a certificate indicating that the mentally disordered person has been examined and meets the criteria for involuntary admission. Involuntary assessments are usually authorised by a physician who has examined the person, a judicial warrant, or a police officer without a warrant under specific circumstances (Gaudet 1994:20). In all provinces and territories, a psychiatric examination is required before a person is involuntarily admitted and detained. Under Quebec legislation, a person cannot be admitted involuntarily without a psychiatric examination; however, if a physician finds that the person poses a serious threat to himself/herself or others, that person can, under section 21, be held for 24 hours in order to undergo a psychiatric examination (Gaudet 1994:20). Involuntary admission in Quebec requires two psychiatric assessments (with the same conclusion) within 96 hours (Gaudet 1994:20, 21). In Ontario, however, one physician may give authority for involuntary admission based on the potential danger posed by the person[6] (Gaudet 1994:21). Thus, in Ontario and Quebec, efforts to involuntarily admit a chronically mentally ill family member by the women in this study may be challenged and met with resistance and may prove to be frustrating for these women.

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[6] In terms of involuntary admissions and detention criteria for the mentally ill, the Uniform Mental Health Act provides authority to designated health professionals and physicians to require that the mentally ill person undergo psychiatric assessment, but authority to involuntarily admit the person is restricted to physicians (Gaudet 1994). A physician would have the authority to determine whether a person should be assessed in a psychiatric facility for possible admission as an involuntary patient and upon assessment, the psychiatrist must be of the opinion that the person is suffering from a "mental disorder," and must have a "reasonable" cause to believe that the person is at risk of injury to himself/herself or that another person is likely to suffer an injury.

In terms of "informed consent" in Ontario and Quebec, mental health legislation in these provinces has established the following principles to decide whether consent from a person who is mentally ill is valid: the patient has been provided with the information that a reasonable person in his position would require to assess the particular risks in the proposed treatment; the patient is mentally competent to authorise treatment; the consent has been freely given; the authorisation for treatment is specific to the procedure to be performed and the patient has had the opportunity to ask questions and to receive comprehensive answers (Gaudet 1994:22) These principles do not include an obligation to ensure that the mentally ill person understands the treatment that they are consenting to nor the potential long-term effectiveness and side effects of the treatment after discharge,[7] despite the importance of this understanding to all chronically mentally ill family members as well as the women in this study.

Currently, consent is necessary before a mentally ill person can receive treatment in Quebec (Gaudet 1994:22). In Quebec, treatment can be given without consent only in an emergency situation, where a psychiatrist believes, "on reasonable and probable grounds", that the patient is in imminent danger. Similarly, in Ontario, treatment can be given by a psychiatrist without consent from a person who is mentally ill only if the person is suffering and is at risk if the treatment is not administered promptly (Gaudet 1994:23). Thus, in Ontario and Quebec, efforts to administer treatment to chronically mentally ill family members by women in this study without their consent may be challenged and met

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[7] Under the Uniform Mental Health Act, a person who is "mentally incompetent" is not able to give an informed consent (Gaudet 1994).

with resistance and may prove to be frustrating for these women who are left to rely solely on the judgement of a psychiatrist in determining "need" in order to administer involuntary treatment, as required by the provincial mental health legislation of both provinces.[8]

The legitimate authority to diagnose mental illness and prescribe medications rests with psychiatrists and medical practitioners while the women in this study are given the responsibility of managing symptoms and behaviours of their chronically mentally ill family members. As Foucault (1980:205) explains, the medical model of madness views mental illness as "...not foreseeable by any of those persons of good sense who claim to be able to recognise it. Only a doctor can spot it, and thus madness becomes exclusively an object for the doctor, whose right of intervention is grounded by the same token."

In Ontario and Quebec, the substitute consent-giver must base consent on the best interests of the mentally incompetent patient with more detailed criteria of duties and responsibilities (Gaudet 1994:24). Any wishes the mentally incompetent person may have expressed at an earlier time while competent are to be honoured in these provinces (Gaudet 1994:24). In Ontario (under the new Health Care Directives Act) a mentally competent person may make an advance designation as to the substitute consent-giver in the event the person becomes mentally incompetent[9](Gaudet 1994:24).

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[8] Under the Uniform Mental Health Act, an involuntary patient has the right not to be given psychiatric treatment or other medical treatment without his consent, a consent made on the behalf, or an order of the review board authorising such treatment (Gaudet 1994). Before authorisation, the review board must be satisfied that the mental condition of the patient will either be substantially improved by the treatment or will not improve without the treatment, and that the benefit of the patient will outweigh the potential risk of harm. Medical treatment may be given without consent where the physician has reasonable and probable grounds to believe that there is imminent and serious danger to the life, a limb or a vital organ of the patient requiring immediate medical treatment. However the opinion of a second physician should be required before the treatment may begin.

[9] Under the Uniform Mental Health Act, an adult patient of a psychiatric facility who is mentally

The legislation of Ontario presents a definition of "mentally competent" as the ability to understand the nature of the illness for which treatment is proposed as well as the ability to appreciate the consequences of giving or withholding consent (Gaudet 1994:24). There are no specific provisions for establishing mental competence to consent to treatment in Quebec[10] (Gaudet 1994:25). Thus, in Ontario and Quebec, efforts by the women in this study to determine mental competence in order to obtain consent to treatment from their chronically mentally ill family members may be challenged and met with resistance and may prove to be frustrating for these women given the vague or absent definitions of "mental competence" in the provincial mental health legislation of both provinces.

Currently, most provinces and territories include confidentiality provisions in their mental health legislation, despite the fact that confidentiality is required under professional codes of medical ethics. Information about hospital patients is gathered and provided to facilitate effective treatment for the patient, in some cases after the patient has been discharged to a community facility. Hospital staff have a strict duty to keep all information

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competent to do so has the right to appoint, in writing, a person to make decisions on behalf of that involuntary patient (Gaudet 1994). Consent to treatment may be given or refused by a mentally competent adult who is willing to act on behalf of the involuntary patient who is mentally incompetent. This person may be a guardian appointed under the Act or by the court, or may be a person living in a conjugal relationship with the patient, or any close relative. The responsibilities of the substitute decision-maker are that, where the wishes of the patient are clearly known, the decision-maker must give or refuse consent in accordance with those wishes; or, if the wishes are not known, the decision-maker has an obligation to give or refuse to consent on the basis of the best interests of the patient. Substitute consent provisions are included in the legislation of all provinces and territories (with the exception of British Columbia and Newfoundland) and can serve as a highly effective manner of involving a female family caregiver in the care of their chronically mentally ill family member, providing that they serve their family members best interests.

[10] In terms of mental competence to consent to treatment, a mentally "competent person," under the Uniform Mental Health Act, is one who is able to understand the subject matter of the consent and is able to appreciate the consequences of giving or refusing consent (Gaudet 1994:24).

from psychiatric records confidential, in consideration of the mentally ill person and the potentially severe consequences of the improper release of information.[11] Thus, in Ontario and Quebec, efforts to monitor the medical file information of chronically mentally ill family members by the women in this study without their consent may be challenged and met with resistance and may prove to be frustrating for these women who are left to rely solely on their own current and previous observations of manic and depressive episodes and any communication with psychiatrists and/or physicians that the chronically mentally ill family members permit.

In Ontario, a person is entitled to examine and copy his/her clinical record. This applies only to a person who is mentally competent (Gaudet 1994:25). As well, clinical records in psychiatric facilities may not be disclosed to third parties except with the consent of the competent patient or a substitute on behalf of the incompetent patient as authorised under the Mental Health Act (Gaudet 1994:25). Disclosure without consent is restricted to a few specified purposes such as research and court orders (Gaudet 1994:25). Even when a clinical record is invoked, the court will only require disclosure if, after an in-camera hearing, it determines that disclosure is essential in the interest of justice (Gaudet 1994:25).

In Quebec, an involuntary patient must be told of the arrangements regarding

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[11] Under the Uniform Mental Health Act, a mentally competent adult has the right to examine and copy the clinical record of his examination, assessment, care and treatment in a psychiatric facility(Gaudet 1994). The chief administrator must give the person access to the record within seven days of the request (Gaudet 1994). The review board may withhold information from the person if the disclosure is likely to result in serious harm to the treatment or recovery of the person, or is likely to result in serious physical harm to another person (Gaudet 1994).

his/her treatment and recovery, unless his/her mental condition precludes the use of such information, or if it would be harmful for him/her to have knowledge of his condition (Gaudet 1994:26). Although in many jurisdictions access to a psychiatric clinical record is a right, under certain circumstances a mental health facility can refuse to provide the information (Gaudet 1994:26). In Ontario, the criteria for withholding clinical records from a patient include the likelihood of serious harm to the treatment or recovery of the patient, and the likelihood of serious physical or serious emotional harm to another person. The onus is on the psychiatric facility to apply to the review board for permission to withhold records from the patient (Gaudet 1994:26). Thus, under the provincial mental health legislation in Quebec and Ontario, women in this study would require consent of the competent patient or a substitute on behalf of the incompetent patient in order to review clinical records in psychiatric facilities. This request for consent by the women in this study may be challenged and met with resistance and may prove to be frustrating for these women.

There is the general right to the review of any decisions in Quebec for every person who is dissatisfied with a psychiatric decision rendered (Gaudet 1994:26). In Ontario, a person who questions the opinion of the attending psychiatrist in declaring a patient mentally incompetent may apply for a review of that opinion (Gaudet 1994:26, 27). In Ontario, a person can also apply to the review board for a review of an involuntary admission and renewal of admission (Gaudet 1994:27). Not all of the review provisions in the various pieces of legislation refer to the right of the patient (Gaudet 1994:27). In Ontario, in the case of involuntary admission, there is a mandatory review after each forth renewal of the involuntary admission with a maximum interval of about a year[12] (Gaudet 1994:27). The review process of a patient's status to determine whether the prerequisites for admission as an involuntary patient were met when the certificate was issued and continues to be met, does not include the women in this study. This request to be involved in the review process by women in the study may be challenged and met with resistance and may prove frustrating for these women.

Mental health promotion and caregiving require that women as primary family caregivers ensure that chronically mentally ill family members continue to comply with medical care, receive medical care when it is required, that they have adequate food, shelter and clothing and they must ensure the prevention of harm of the individual to themselves, to family members and others, through things like the prevention of violence, and drug and alcohol abuse. How can the women in this study do this in the present context when female family caregivers are refused information from psychiatrists and physicians? When they don't have adequate information about the family member? When mental health services are inadequate? When female family caregivers accompany family members to emergency but are often excluded from meeting with psychiatrists and physicians? When female family caregiver knowledge is ignored much to the detriment of all family members? When female family caregivers, psychiatrists and physicians are bound by contradictory legislation and policy that

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[12] Under the Uniform Mental Health Act, the review board promptly reviews a patient's status to determine whether the prerequisites for admission as an involuntary patient were met when the certificate was issued and continues to be met (Gaudet 1994). Each party is entitled to be represented by counsel in a hearing before the board, and is also entitled to appeal any decision made by the review board (Gaudet 1994). By making medical decisions reviewable, a mental health statute can provide a means by which the patient's views may be weighed to assure that the objects and requirements of the statute and the requirements of fundamental justice in the Charter are being met (Gaudet 1994).

recognises the right to refuse care as more important than the right to care even in situations where intervention is required? These critical questions are only addressed and paid lip service to every now and again; most often it takes a heinous crime or bizarre act by a chronically mentally ill person to shock the public and inspire a spasm of governmental concern about deinstitutionalization, cutbacks to mental health services and, mental health policy and legislation. It is a cycle of mindfulness and forgetfulness that plays out in cities across Canada, neglectful of long term financial costs to the state and personal and financial costs to the chronically mentally ill, women as their primary family caregivers and society as a whole.

1.4 Women as Primary Family Caregivers of Chronic Manic Depressives and Schizoaffectives

While I assert in this study that women are the primary caregivers of mentally ill adults or children, their experiences have not yet been previously studied as case studies of in-depth qualitative interviews in sociological research. However, indirect evidence supports the assertion that women are the primary caregivers of the mentally ill (Ascher-Svanum and Sobel 1989:843). According to Ascher-Svanum and Sobel (1989:843) in surveys of the needs of family members of psychiatric patients, up to 86 percent of the responses have been from women and similarly, when patients were asked in interviews about the family caregiver most likely to be affected by their returning home, the great majority of caregivers were women.

The terms caregiver(s) and caregiving are used interchangeably in this thesis in a conceptual manner as it "frequently denotes situations in which someone may suffer or even die if not provided with care. These relationships usually involve one healthy adult while the other is a child or sick, elderly, or disabled person" (Baines 1991:14, 15). The term "chronic" is defined in this thesis according to Rosen (1990:2) as mental disorders that "reoccur periodically or exist over a long period." The terms "mental disorder", "mental illness" and "madness" are used interchangeably and defined consistently and conceptually in this thesis according to the definition provided by Epp (1988:8) as "a recognized, medically diagnosable illness that results in the significant impairment of an individual's cognitive, affective or relational abilities." Finally, the term "mental health problem" is defined in this thesis according to Epp (1988:8) as "a disruption in the interactions between the individual, the group and the environment. Such a disruption may result from factors within the individual, including physical or mental illness, or inadequate coping skills. It may also spring from external causes, such as the existence of harsh environmental conditions, unjust social structures, or tensions within the community." Although the terms "mental health problem" and "mental disorder" defined by Epp (1988:8) are socially constructed and predicated upon the medical model (see American Psychiatric Association 1952, 1968, 1987, 1994) several health policy documents and researchers (see Epp 1986, 1988; American Psychiatric Association 1952, 1968, 1987, 1994a, 1994b; Rosen 1990 and Thompson et al. 1984) have identified problematic symptoms and episodes that contribute or emerge from these mental "problems and disorders" as challenging the "mental health" of both the mentally ill and their family caregivers.

The diagnostic categories and psychiatric labels of mental illnesses including "bipolar disorder" and "schizoaffective disorder" in the American Psychiatric Association's (1952, 1968, 1987, 1994) diagnostic manuals are also socially constructed and predicated upon the medical model. Sociology's labeling theorists (Lemert 1951; Becker 1963; Szasz 1967, 1973, 1991; Scheff 1984) regard these categories and labels as social constructions and the classification of psychiatric disabilities a social act whereby the diagnostic psychiatric label imparts a defective personal identity to the patient. Labeling theorists argue that each of these categories and labels in current diagnostic manuals that are affixed to the mentally ill "tends to become a self-fulfilling prophecy as well as a lifetime sentence" (Johnson 1990 61). This "is one of those uncomfortable insights that never quite gets argued away by its detractors [labeling theorists], probably because it is essentially true" (Johnson 1990:61). However, "even if accurate, the idea that mental illness is a stigmatizing label stuck on people for political reasons is not particularly helpful when one must deal with the flesh-and-blood patients, who may well be the victims of labeling, but whose problems are very real nonetheless" [13] (Johnson 1990:61) with very

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[13] Several other publications (Epp 1986, 1988; American Psychiatric Association 1952, 1968, 1987, 1994a, 1994b; Rosen 1990 and Thompson et al. 1984) support Johnson's assertion that the problems of the mentally ill are associated with their symptoms and the implications for their family caregivers are "very real" and present, as is the discourse around psychiatric labeling. This thesis concerns itself with the "very real" problems of the chronically mentally ill in that it examines of female family caregivers and the governance of madness, turning to a materialist method as Marx and Engels formulated in *The German Ideology* (1970). As Smith (1987:123) explains "For theirs [Marx and Engels] is an ontology that first shifts us out of the discourse among texts as a place to start. The premises they declare are not in imagination. They insist we start in the same world as the one we live in, among real individuals, their activities, and the material conditions of their activities. What is there to be investigated are the ongoing actual activities of real people. Nothing more or less. We are talking about a world that *actually happen* and can be observed, spoken of, and returned to check up on the accuracy of an account or whether a given version of it is faithful to how it actually works (in principle at least; the practice may at times prove more complicated)."

real costs and consequences for women as their primary family caregivers.

The chronic mental illnesses that pose the greatest challenges to female family caregivers governance of madness and to the coping resources of affected individuals and these caregivers are manic depression, schizophrenia and dementia (Epp 1988:17). As Duke and Hochman (1992:209) argue:

> ...I empathize with family members of anyone who is manic-depressive. They are the innocent bystanders who are being ravaged by this thing, and they don't have the benefit of the insight of the person who is feeling the extreme mood changes. They can't begin to understand how someone can cry for three months in a row or fly off the handle at the flip of a switch. I see family members desperate to help and showing loyalty and love and stamina--and they're in the dark. Until someone gives them the proper diagnosis, they are suffering just as much as the person in depression or in mania. But they're not lying in bed. They have to go about their lives, and no one is paying a whole lot of attention to them. The person in depression, whether aware of it or not, is getting a great deal of attention. Not that it helps. But who's giving attention to the attention-giver? Who's replenishing that well?

Approximately one percent of the population suffers from manic depression, a severe long-term mental illness (American Psychiatric Association 1994a:26; Thompson at al. 1984:5) and "by the time it is diagnosed, it has already caused a great deal of grief and suffering to the patient and his family. That happens because the earlier or cyclothymic phases of the condition go unrecognized" (Duke and Hochman 1992:38).

Although lay people ordinarily use the term "manic depressive illness", psychiatric professionals are increasingly using the term "bipolar disorder" as is demanded by current diagnostic manuals (American Psychiatric Association, 1952, 1968, 1987, 1994). Manic depression or "bipolar disorder" is a disturbance of a person's mood characterized by alternating episodes of depression and mania (American Psychiatric Association

1994a:350-363; Hilliard 1992:3). Bipolar refers to the "two poles" of the continuum of moods with depression or feeling down at one end and mania or feeling high at the other end (American Psychiatric Association 1994a:350-363; Hilliard 1992:3). Switching from depression to mania is referred to as an episode. Episodes are classified as mild, moderate or severe and these mood swings are accompanied by changes in thinking and behaviour (American Psychiatric Association 1994a:350-363; Hilliard 1992:3).

Manic depressive patients suffer from different degrees of mania and psychiatrists classify the severe and heightened mania with swings to depression as Bipolar I and persons with less exaggerated forms of mania (hypomania) before swings of depression are classified as Bipolar II (American Psychiatric Association 1994a:350-363, SerVaas 1996:46). Manic depressives who have had four or more mood episodes in a twelve month period are classified as "rapid cyclers" according to the American Psychiatric Association's DSM IV (1994a:390). Rapid cycling can be applied to individuals classified with Bipolar I and Bipolar II Disorder (American Psychiatric Association 1994a:391).

The chief symptom of a manic episode is an elevated and expansive mood. This mood is thought to progress along a continuum which include: normal states, moderate elations and mania. States of mania are those in which symptoms of moderate elations elevate beyond moderation and start to interfere with social and physiological functions. 'Delirious" or psychotic mania is characterized by severe overactivity, hostile attitudes, destruction of property, assaultiveness, paranoid delusions and/ or hallucinations. Specific symptoms influence areas of feelings, thinking, body and behaviour which have a quality of being in high gear and bursting at the seams with feelings of elevated mood, feeling high, elated, euphoric and ecstatic.

Symptoms of episodes of mania include irritability, excessive anger over trivial things, hostile, overreacting to stimuli as well, labile, rapid emotional changes as in feeling happy one minute and then angry the next for no apparent reason (Hilliard 1992:6).

Symptoms of episodes of mania can affect thoughts of inflated self-esteem, grandiosity and thinking one is more powerful than one really is. Ideas pour in at an incredible pace and mental associations after associations occur so that speech can be full of jokes, plays on words and amusing irrelevancies. Symptoms of episodes of mania can also affect thoughts in misinterpretation of events, distortion of the meaning of ordinary comments, distractibility, racing thoughts and flights of ideas with thoughts jumping quickly from one topic to another. Symptoms of episodes of mania include poor judgement when one will probably not recognize that one is ill and is apt to refuse treatment and will blame others for things that go wrong. Symptoms of episodes of mania also include a loss of touch of reality, hearing voices (hallucinations) or having strange ideas (delusions) about being persecuted and being controlled. Symptoms of episodes of mania can also affect the body in excessive energy and decreased sleep with sometimes only a couple of hours a night and a heightening of all senses especially in the perception of colours and light (Hilliard 1992:6).

Symptoms of episodes of mania can affect the behaviour through the involvement in grandiose money making schemes, overspending, giving money away, going on shopping sprees, incurring heavy debts, moving from one activity to another without stopping and a compulsive desire to be socially involved prompting telephone calls to friends at all hours of the night, often to discuss plans. In episodes of mania, the individual may be socially intrusive, headstrong, targeting the self-esteem of others, alienating family members, behaving angrily and demanding. As well, talking more than usual, sometimes loudly and quickly, taking a new interest in collection of clothes, possessions or other objects, increased sexual activity, wanting to engage in sexual intercourse several times a day or picking up partners indiscriminately are symptoms of episodes of mania (Hilliard 1992:7).

The symptoms of depressive episodes include feelings of a depressed mood that are often characterized by feeling sad, low, blue, hopeless, helpless, useless, guilty, ashamed and remorseful. Since feelings of sadness, disappointment and frustration are a part of normal living, the diagnosis of severe depressive states is made only if such states are intense, pervasive, persistent and interfere with usual social and physiological functioning (Hilliard 1992:3). Symptoms of depressive episodes affect feelings, thinking, body and behaviour. The individual may experience a loss of interest in work, loss of feelings for family and friends, anxiety, fears and worries. Feelings of depressed mood may also be characterized by feelings of worthlessness, undeserving of help, pessimism, loss of interest in sex and the inability to experience pleasure and have fun. Symptoms of depressive episodes affect the thoughts of the individual in slowed thinking, difficulty in concentrating, in making decisions and mixed-up thoughts. The individual may be preoccupied with failures, experience a loss of self-esteem and may have an obsession with certain thoughts that one cannot seem to turn off such as harming oneself or others. The individual may experience a loss of touch with reality, hear voices (hallucinations) or have strange ideas (delusions) (Hilliard 1992:4). Symptoms of depressive episodes can affect behaviours with slowed talking, moving, withdrawal from social contacts and crying easily or not at all even though one might like to and during depressive episodes the individual may excessively use alcohol and/or non-prescription drugs (Hilliard 1992:5).

According to Jamison (1996:53), a manic depressive, '[t]here is a particular kind of pain, elation, loneliness, and terror involved in this kind of madness [manic depression]." As Jamison (1996:53) explains:

> When you're high it's tremendous. The ideas and feelings are fast and frequent like shooting stars and you follow them until you find better and brighter ones. Shyness goes, the right words and gestures are suddenly there, the power to captivate others a felt certainty. There are interests found in uninteresting people. Sensuality is pervasive and the desire to seduce and be seduced irresistible. Feelings of ease, intensity, power, well-being, financial omnipotence, and euphoria pervade one's marrow. But, somewhere, this changes. The fast ideas are far too fast, and there are far too many; overwhelming confusion replaces clarity. Memory goes. Humor and absorption on friends' faces are replaced by fear and concern. Everything previously moving with the grain is now against - you are irritable, angry, frightened, uncontrollable, and enmeshed totally in the blackest caves of the mind. You never knew those caves were there. It will never end, for madness carves its own reality.

Further "[i]t goes on and on, and finally there are only others' recollections of your behavior - your bizarre, frenetic, aimless behaviors - for mania has at least some grace in obliterating memories. What then, after the medications, psychiatrist, despair, depression, and overdose?" (Jamison 1996:53)

The most commonly used forms of treatment for manic depression are medication, psychotherapy and electroconvulsive therapy (ECT), these may be used individually or in combination with one another and while effective treatment exists for some manic depressives, there is no cure and even with optimal treatment most patients require some level of longitudinal psychiatric care (Thompson et al. 1984:6; American Psychiatric Association 1994b:26). Hanna (1996b:9) describes the difficult challenges in treating manic depression in that:

> Dealing with ... manic depression...often seems like a trial and error

> approach by both the patient and doctor. Some people find a great technique or resource for dealing with the difficult times and live a healthy and productive life. Others find it a struggle and seemingly constant battle with moods, medications, dietary restrictions, and erratic behaviour.

Unfortunately, there is a general tendency for therapists to discard manic depressive patients because "so little is fed back into therapy when the patient is depressed, and because, in the manic phase, their exaggerated and incessant demands are difficult to tolerate" (Davenport et al. 1979:34). Without treatment, manic depressives face substantial and prolonged distress and impairment, as well as the risk of significant morbidity and mortality. Further, without effective treatment, there is a high suicide risk (Kusumakar et al. 1996). According to the American Psychiatric Association (1994b:26) and Jamison (1995:44), in mixed states, filled with manic energy and morbid thoughts, manic depressives are most likely to attempt suicide and succeed.

The essential feature of manic depression with schizophrenic tendencies or "schizoaffective disorder" is a continual period of illness during which at some time, there is a major depressive, manic or mixed episode concurrent with two or more of the following symptoms of schizophrenia: delusions, hallucinations, disorganized speech such as frequent derailment or incoherence, grossly disorganised or catatonic behavior, negative symptoms such as affective flattening, and alogia or avolition each present for a significant portion of time during a one month period, or less time if successfully treated (American Psychiatric Association 1994a:285, 292). In addition, during the same period of illness, delusions or hallucinations are present for at least two weeks in the absence of prominent mood symptoms. Mood symptoms are present for a substantial portion of the total duration of schizoaffective disorder (American Psychiatric Association 1994a:292). There are two subtypes of schizoaffective disorder based on the mood component of the disorder: bipolar type applies if a manic episode or mixed episode is part of the presentation and major depressive episodes may also occur, and the depressive type applies if only major depressive episodes are part of the presentation.

According to Gulliver (1996) 40-65% of adults with chronic mental illness (such as chronic bipolar disorder and schizoaffective disorder) either reside with their families or receive primary care-management from their families, with the majority (70 per cent or more) of caregivers being women (Armstrong 1994:99). Female family caregivers of the chronically mentally ill are likely to face the greatest challenges of all family members of the mentally ill since they "generally assume the responsibilities of care, they tend to bear the majority of the burden for their ill relatives" (Solomon and Draine 1995:420; see also Cook, 1988; Crotty and Kulys, 1986; Noh and Turner, 1987; Thurer, 1983). Rosen (1990:2) explains that:

> ...a lot of energy, as a family member, is spent looking after the needs of the ill family member - making phone calls, trying to find resources, taking people to appointments, making sure that the medication is being taken. Second, I think you [family caregiver] spend a lot of your time picking up the pieces of plans not finished, relationships broken off, and friends who are embarrassed or insulted by a tirade of rage. You must pick up the pieces of family relationships when you don't show up for a family reunion because you had a fight the moment before. You also pick up the pieces, literally of things that are broken around the house.

Given these conditions, as Armstrong and Armstrong (1996:141) argue, the shift to "community based care" and the process of dehospitalization or deinstitutionalization has not primarily been about returning care to the home but rather about "turning the home into an institution [in which female family members serve as primary caregivers to mentally ill family members] without adequate resources."

Evidently, an understanding of the complexities involved in caregiving by women as primary family caregivers of the chronically mentally ill and its accompanying costs and benefits have not been incorporated into the design and implementation of Canada's mental health delivery system, mental health policy and legislation. Significant contributions will be made to both a theoretical and practical understanding of these complexities in this qualitative study through the use of a feminist political economy framework and governance by a sociologist and feminist with: 1) a belief that women all over the world face some form of oppression or exploitation 2) a commitment to uncover and understand what causes and sustains oppression and 3) a commitment to work individually and collectively in everyday life to end all forms of oppression, whether based on gender, class, race or culture[14] (Maguire 1987:5). In the following chapter, I will present a discussion of the guiding theoretical framework and how it serves to frame the context for the design and analysis of my study presented in Chapters 3 and 4 respectively.

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[14] As Reinharz (1992) argues, women who teach, research, and publish about women, but who are not involved in any way in making radical social and political changes, women who are not involved in making the lives of living, breathing women more viable or lifting oppression as priorities are not part of the actual feminist movement.

2.0 CHAPTER TWO: THE GUIDING THEORY; FEMINIST POLITICAL ECONOMY AND GOVERNANCE

The conceptual and theoretical tools from sociological tradition are inadequate to examine the post-1960s deinstitutionalization experiences of women as primary family caregivers of those with chronic mental illness. Contemporary sociological research on mental illness has failed to move beyond the work of labelling theorists (Lemert 1951; Becker 1963; Szasz 1967, 1973, 1991; Scheff 1984) on deviance, and the research of Brill and Patton (1957, 1962), Goffman (1961), Stanton and Schwartz (1964), Strauss et al.(1964), Belknap (1956), Caudill (1958) and Dunham and Weinberg (1960) on the negative effects of institutionalization for patients. This focus has led them to ignore a major social consequence of deinstitutionalization that has been the discharge of patients to the care of women. Therein lies the justification for the use of a feminist political economy framework and Foucault's (1991:102) notion of governance in this study; moving beyond the inadequate and somewhat outdated conceptual and theoretical tools of these sociologists who conducted research in an era when long term psychiatric institutionalization was a fiscal possibility and its effects on patients was a phenomenon of concern.

Political economy is a more pragmatic, holistic and interdisciplinary framework from which to examine the post-1960s deinstitutionalization experiences of family caregivers of those with chronic mental illness in that it strives to connect the economic, political, and cultural/ideological moments of social life and understand society from a materialist perspective. In its early development, political economy "assumed the existence of two largely separate spheres: a public sphere located in the formal economy and dominated by men, and a private sphere confined to the household and managed by women" (Armstrong and Armstrong 1985:167). Research developments in political economy have recognized that the public and private spheres were never separate and the apparent distinction between the household and the outside world continue to erode (Armstrong and Armstrong 1985:168). These developments allow the present researcher to examine how the ongoing public sphere developments of cutbacks to the provision of health and mental health services impact the private sphere of households and female family caregivers of the chronically mentally ill in particular, and recognize that the two spheres are undeniably linked.

As Armstrong and Armstrong (1985:176) maintain, there is a need to continue developing the traditional political economy framework and work towards "a more wide-ranging and imaginative theory and practice, in order to analyze and transform all aspects of political economy" with "such theory and practice" taking "sex differences into account." Thus, I use an interdisciplinary feminist[15] political economy framework and governance as a "wide-ranging and imaginative theory and practice". As Reinharz argues (1992:250) "[f]eminists seem particularly drawn to work on the borders of, and outside,

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[15] In this thesis I use a feminist perspective and strive to maintain following the principles of feminist research as outlined by Reinharz (1992:249, 251) "[f]eminist researchers almost always utilize feminist theory to frame questions and interpret their data. Frequently, in feminist research, gender of femaleness is the variable and power/experience/action and the relation under investigation. Feminist social research utilizes feminist theory in part because other theoretical traditions ignore or downplay the interaction of gender and power. Some feminist researchers write that data in feminist research *must* be explained by feminist theory. In addition to the connection with theory, much feminist research is connected to social change and social policy questions. Explicit policy recommendations are typical in feminist research."

their fields. As 'connected knowers' we [feminists] live in two worlds and find ways of bridging or blending disciplines."

The use of an interdisciplinary feminist political economy framework and governance in this thesis draws upon a feminist "sociological imagination" to bridge and examine critical linkages between "the public issues of social structure" and "the personal troubles of milieu" (Mills 1959:8), the public and private sphere, structure and agency,[16] and the state and civil society[17] while taking "sex differences into account" (Armstrong and Armstrong 1985:176). As Mills (1959:10) contends, what all of us experience (including women as primary family caregivers) "in various and specific milieu...is often caused by structural changes." Further "[t]o be aware of the idea of social structure and to use it with sensibility is to be capable of tracing such linkages among a great variety of milieux. To be able to do that is to possess the sociological imagination."

In this study, forging these linkages are critical for three reasons. The first reason that this linkage is critical is to develop an adequate model in this study to examine how the macro caregiving context has created problems, issues and tensions on a micro level for female family caregivers. The second reason that this linkage is critical is to develop an

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[16] For the purpose of this thesis, "agency/structure refers to agency in terms of intentionality and the causal powers of actors (or agents), whereas structure is conventionally defined in terms of constraints upon actors" (Sibeon 1996:120).

[17] Foucault's notion of governance allows the researcher to traverse "the distinction between state and civil society" in that governance is "to be found on both, not just on one side, of this evocative dichotomy" (Hunt 1993:306). Female family caregivers represent part of civil society in that civil society lies apart from the realms of the market and the government, and possesses a different ethic. The market is governed by the logic of economic self-interest, while government is the domain of laws and with all their coercive authority (Bradley 1996). However, civil society is the sphere of our basic humanity, the personal, everyday realm that is governed by values such as responsibility, trust, fraternity, solidarity and love (Bradley 1996).

adequate model in this study to examine the female family caregiver governance of chronically mentally ill family members to manage the contradictions in their roles as primary family caregivers and as state designated mental health promoters. Finally, these linkages are critical to feminist research and social change as they attempt "to demonstrate the reach of the political areas typically assumed to be personal, in addition to areas always thought of as political" in that "[a] feminist perspective means being able to see and analyze politics and gender conflict" (Reinharz 1992:249-250).

According to Armstrong and Armstrong's (1985:176) feminist political economy perspective "the personal is political...the private is invariably linked to the public...any analysis that fails to take this connection fully into account is necessarily flawed." While a feminist political economy framework is effective in linking the private to the public and providing an understanding of the social, political and economic problems, issues and tensions created for women as primary family caregivers by the macro caregiving context, the framework has its limitations. Feminist political economy has yet to develop a purposeful analytical model of inquiry for research into structure and female family caregivers agency and power that can be used to examine the complex forms of power that these women exercise over their family members in order to manage the social, political and economic problems, issues, tensions and contradictions that are present at both the micro and macro level.

The complementary use of the notion of governance in this thesis overcomes these limitations by enhancing the feminist political economy framework and serving to build a more purposeful analytical model of inquiry for feminist research into structure and female family caregiver's agency and power since "governance is marked by an attempt to hang onto both structure and agency" (Hunt 1993:269). The notion of governance as it is used to understand a "very specific albeit complex form of power" that is exercised by women as primary caregivers of their chronically mentally ill family members "opens up a space that allows us to break with the common-sense perception that only governments govern" (Hunt 1993:290).

Governance, according to Foucault (1991:102), is "the institutions, procedures, analyses, and reflections, the calculations and tactics that allow the exercise of this very specific albeit complex form of power." Governance and the feminist political economy framework serves as a purposeful analytical model of inquiry for feminist research into structure and female family caregiver's agency and power, in that feminist political economy and "working through the problematic of governance will encourage and facilitate the bringing together within the same conceptual and political agenda the politics of everyday life [for women as primary family caregivers] and the condensation of power in and around the state" (Hunt 1993:309).

Women are increasingly expected by the state to take on the additional caring work of family members with chronic mental illness given the ongoing post-1960s deinstitutionalization process, growing fiscal crisis of the state and ensuing cutbacks in health and mental health care. Scull (1977, 1985, 1986) and Armstrong and Armstrong (1996) note the causes and consequences of the post-1960s deinstitutionalization process in that the post-war period's growing fiscal crisis of the state resulted in efforts to reduce costs and in response to the imperative of cost cutting, the state began to divest itself of responsibility for the institutional care of the mentally ill. The fiscal crisis has both been blamed on social spending and used as a justification for cuts in spending (Armstrong and Armstrong 1996:6,7) including cutbacks in the provision of health and mental health services. As the Ministers of Health and Finance (1992:35, 36) maintain:

> Certainly, the end of the high economic growth rates of the 1960s and 1970s provided provinces with an economic rationale for taking a harder look at their health care systems. Many of the reform measures which have been implemented in the late 1980s and early 1990s respond to cost pressures identified by these reviews (e.g., new technologies, health human resources). However, the most significant outcome of these reviews have been the creation of a consensus among governments on the need to change the direction of health care away from a focus on institutions and treatment towards a greater emphasis on community-based care and health promotion and prevention. This implies that the maintenance of an adequately funded and efficient health care system, and the reaffirmation of historical national health insurance principles are preconditions for further change. In light of this, cost containment is likely to remain an important issue during the 1990s, as continued slow economic growth coupled with high growth in health care expenditures places additional pressures on the fiscal situations of the federal and provincial governments.

Further, '[w]ith the development of new psychiatric drugs which enhance coping capabilities and an increase of non-institutional support services. a significant number of patients could be discharged from provincial psychiatric facilities and integrated into the community" (Ministers of Health and Finance 1992:21,22).

Northcott (1994:77) maintains that over time, financial cutbacks have eroded and will continue to erode the federal transfers of cash to the provinces, leaving the provinces to finance medicare through the powers of taxation relinquished to them by the federal government. In the face of declines in federal funding, provincial governments have been left to manage the growing crisis in health care of rising costs and the increasing gap between the health needs of the population and the capacity of the existing health care system to satisfy them. In *The Fiscal Crisis of the State*, O'Connor (1973) effectively argues, from within a political economy framework, that capitalist states perform accumulation and legitimation functions. They 'help create the conditions for private profit making by providing roads, sewers, highways, utilities, communication services, airports, research, and an educated workforce" and 'help insure social harmony by providing a justice system and services for citizens, and by promoting a shared value system'(Armstrong and Armstrong 1996:6). The state's two roles of accumulation and legitimation are linked since 'states vary their supports for businesses and for workers, as well as their stated values, to accommodate changes in the needs of organizations seeking profit" (Armstrong and Armstrong 1996:6). O'Connor argues that states were paying for more and more of the costs of accumulation while continuing to allow the profits to be collected and controlled privately. Fiscal crises were inevitable as state expenses were increasing more rapidly than revenues. Indeed, twenty years later in Canada 'the economic boom has ended in an economic bust"(Armstrong and Armstrong 1996:6,7). As Armstrong and Armstrong (1996:6) point out, health care services (and mental health care services) are very much part of such capitalist states discussed by O'Connor and state expenditures on the provision of these services are likely to shift with changes in accumulation and legitimation.

Provincial efforts to control the crisis of rising costs of care in Canada have been largely through attempts to reduce number/duration of contacts with the health care system during illness, attempts to reduce the costs per contact, and most recently the reduction of the amount budgeted on health care (Dickinson 1994:106). As Table 1 clearly shows, the largest category of health resources is expended on hospital care. In 1997, for example, it is estimated

TABLE 1

Total Health Expenditure by Use of Funds, Canada, 1975-1997 - Current Dollars

	Hospitals	Other Institutions	Physicians	Other Professionals			
				Dental Services	Vision Care Services	Other	Sub-Total
Year	A	B	C				D
			($'000,000)				
1975	5,514.3	1,124.3	1,839.9	740.1	226.1	128.4	1,094.6
1976	6,408.7	1,367.7	2,071.1	867.4	260.1	145.5	1,273.0
1977	6,841.6	1,575.9	2,284.4	1,033.0	295.8	162.5	1,491.3
1978	7,444.3	1,850.3	2,566.7	1,189.4	336.0	186.3	1,711.7
1979	8,176.2	2,169.5	2,857.1	1,372.2	365.7	219.2	1,957.1
1980	9,399.2	2,536.2	3,287.5	1,590.3	414.3	255.4	2,260.0
1981	11,134.5	2,882.0	3,824.9	1,809.7	513.6	303.7	2,626.9
1982	13,238.2	3,335.9	4,420.8	2,070.4	609.8	357.3	3,037.4
1983	14,560.6	3,694.7	5,052.7	2,223.6	715.0	411.6	3,350.2
1984	15,452.1	3,885.8	5,525.9	2,400.3	829.2	452.2	3,681.7
1985	16,386.3	4,078.5	6,046.8	2,709.8	925.8	495.4	4,130.9
1986	17,739.8	4,066.0	6,675.3	2,958.3	1,002.1	560.8	4,521.2
1987	19,113.6	4,307.3	7,342.5	3,202.9	1,075.4	635.6	4,913.9
1988	20,475.8	4,715.9	7,948.1	3,461.8	1,175.7	713.7	5,351.1
1989	22,454.2	5,117.9	8,516.6	3,771.8	1,289.4	830.1	5,891.2
1990	24,051.2	5,720.5	9,258.3	4,072.1	1,388.3	952.2	6,412.6
1991	25,919.4	6,316.0	10,219.7	4,394.5	1,468.6	1,079.5	6,942.7
1992	26,882.6	6,834.2	10,464.0	4,596.8	1,518.9	1,161.4	7,277.1
1993	26,977.8	6,859.6	10,514.9	4,760.2	1,547.4	1,196.1	7,503.8
1994	26,757.8	6,982.5	10,692.8	4,952.2	1,617.9	1,226.4	7,796.6
1995	26,460.5	7,258.4	10,823.5	–	–	–	8,051.9
1996 f	26,070.4	7,497.7	10,911.3	–	–	–	8,363.2
1997 f	25,783.5	7,738.9	11,009.0	–	–	–	8,636.1
			(annual percent change)				
1975	–	–	–	–	–	–	–
1976	16.2	21.7	12.6	17.2	15.0	13.3	16.3
1977	6.8	15.2	10.3	19.1	13.7	11.7	17.2
1978	8.8	17.4	12.4	15.1	13.6	14.6	14.8
1979	9.8	17.3	11.3	15.4	8.9	17.7	14.3
1980	15.0	16.9	15.1	15.9	13.3	16.5	15.5
1981	18.5	13.6	16.3	13.8	24.0	18.9	16.2
1982	18.9	15.7	15.6	14.4	18.7	17.7	15.6
1983	10.0	10.8	14.3	7.4	17.3	15.2	10.3
1984	6.1	5.2	9.4	7.9	16.0	9.8	9.9
1985	6.0	4.9	9.4	12.9	11.6	9.6	12.2
1986	8.3	-0.3	10.4	9.2	8.2	13.2	9.4
1987	7.7	5.9	10.0	8.3	7.3	13.3	8.7
1988	7.1	9.5	8.2	8.1	9.3	12.3	8.9
1989	9.7	8.5	7.2	9.0	9.7	16.3	10.1
1990	7.1	11.8	8.7	8.0	7.7	14.7	8.8
1991	7.8	10.4	10.4	7.9	5.8	13.4	8.3
1992	3.7	8.2	2.4	4.6	3.4	7.6	4.8
1993	0.4	0.4	0.5	3.6	1.9	3.0	3.1
1994	-0.8	1.8	1.7	4.0	4.6	2.5	3.9
1995	-1.1	3.9	1.2	–	–	–	3.3
1996 f	-1.5	3.3	0.8	–	–	–	3.9
1997 f	-1.1	3.2	0.9	–	–	–	3.3

f - Forecast

Source: National Health Expenditures Team. *National Health Expenditures Trends, 1975-1997*. Ottawa: Canadian Institute for Health Information. 1997.

TABLE 1

Total Health Expenditure by Use of Funds, 1975 to 1997 - Current Dollars (cont'd)

Drugs			Capital	Other Health Spending					
Prescribed Drugs	Non-Prescribed Drugs	Sub-Total		Pre-payment Administration	Public Health	Health Research	Other	Sub-Total	Grand Total
		E	F					G	A+B+C+D+E+F+G
				(1'000,000)					
770.6	305.6	1,076.2	536.9	211.8	514.9	94.8	253.1	1,074.6	12,260.9
881.3	316.0	1,197.3	545.3	212.7	630.4	106.7	290.3	1,240.1	14,103.7
985.0	324.5	1,309.5	564.7	248.2	720.4	130.7	335.1	1,434.4	15,501.8
1,049.2	392.8	1,442.0	672.5	257.8	714.7	151.8	360.6	1,484.9	17,172.4
1,159.8	495.5	1,655.3	786.9	286.8	808.1	173.5	422.0	1,690.5	19,292.6
1,295.2	586.3	1,881.5	1,054.4	318.3	950.5	202.0	517.7	1,988.4	22,408.3
1,673.9	655.0	2,328.9	1,206.7	417.3	1,117.2	232.2	678.7	2,445.3	26,449.1
1,920.9	715.0	2,635.9	1,467.1	407.8	1,326.0	258.8	784.9	2,777.5	30,912.9
2,103.8	845.8	2,949.6	1,510.0	434.1	1,423.0	297.9	895.3	3,050.3	34,188.1
2,252.2	1,058.6	3,310.8	1,560.9	520.7	1,577.0	337.8	967.1	3,402.7	36,819.9
2,557.6	1,235.8	3,793.4	1,833.0	555.1	1,760.3	374.3	1,095.5	3,785.2	40,058.1
3,006.6	1,399.0	4,405.6	2,028.2	634.9	1,823.3	436.3	1,254.6	4,149.0	43,583.0
3,278.3	1,621.7	4,900.1	2,058.4	651.8	1,929.4	436.7	1,403.6	4,421.5	47,057.2
3,720.8	1,784.9	5,505.7	2,022.7	808.4	2,117.5	481.4	1,658.1	5,065.4	51,084.7
4,241.6	1,975.6	6,217.2	2,197.9	1,039.5	2,417.8	554.3	1,941.2	5,952.7	56,347.8
4,846.8	2,058.7	6,905.5	2,231.9	1,053.9	2,700.9	640.8	2,280.5	6,676.0	61,258.1
5,437.0	2,236.6	7,673.6	2,131.6	1,154.4	2,962.4	683.2	2,561.5	7,361.5	66,564.5
6,050.1	2,401.6	8,451.7	2,250.6	1,221.2	3,280.5	728.3	2,766.4	7,996.4	70,154.6
6,337.0	2,560.0	8,897.0	2,097.1	1,495.1	3,480.2	760.4	3,205.9	8,941.5	71,791.8
6,492.8	2,586.0	9,078.8	2,304.2	1,663.4	3,601.7	785.7	3,447.8	9,502.4	73,115.2
-	-	9,303.9	2,612.4	-	-	-	-	9,983.2	74,491.8
-	-	9,439.6	2,784.4	-	-	-	-	10,412.4	75,479.2
-	-	9,641.2	3,046.4	-	-	-	-	10,780.7	76,635.3
				(annual percent change)					
-	-	-	-	-	-	-	-	-	-
14.4	3.4	11.3	1.6	0.4	22.4	12.5	14.7	15.4	15.0
11.7	2.7	9.3	3.6	16.7	14.3	22.5	15.4	15.7	9.9
6.5	21.1	10.1	19.1	3.9	-0.8	16.2	7.6	3.5	10.8
10.5	26.2	14.8	17.0	11.2	13.1	14.4	17.0	13.8	12.3
11.7	18.3	13.7	34.0	11.0	17.6	16.9	22.7	17.7	16.1
29.2	11.7	23.8	14.4	31.1	17.5	14.4	31.1	22.9	18.0
14.8	9.2	13.2	21.6	-2.3	18.7	11.5	15.7	13.6	16.9
9.5	18.3	11.9	2.9	6.5	7.3	15.1	14.1	9.8	10.5
7.1	25.2	12.2	3.4	19.9	10.8	13.4	8.0	11.6	7.8
13.6	16.7	14.6	17.4	6.6	11.6	10.8	13.3	11.2	8.8
17.6	13.2	16.1	10.2	14.4	3.6	16.5	14.5	9.6	8.8
9.0	15.9	11.2	1.6	2.7	5.8	0.1	11.9	6.6	8.0
13.5	10.1	12.4	-1.7	24.0	9.7	10.2	18.1	14.6	8.6
14.0	10.7	12.9	8.7	28.6	14.2	15.1	17.1	17.5	10.3
14.3	4.2	11.1	1.5	1.4	11.7	15.6	17.5	12.2	8.7
12.2	8.6	11.1	-4.5	9.5	9.7	6.6	12.3	10.3	8.7
11.3	7.4	10.1	5.6	5.8	10.7	6.6	8.0	8.6	5.4
4.7	6.6	5.3	-6.8	22.4	6.1	4.4	15.9	11.8	2.3
2.5	1.0	2.0	9.9	11.3	3.5	3.3	7.5	6.3	1.8
-	-	2.5	13.4	-	-	-	-	5.1	1.9
-	-	1.5	6.6	-	-	-	-	4.3	1.3
-	-	2.1	9.4	-	-	-	-	3.5	1.5

CIHI 1997

Source: National Health Expenditures Team. *National Health Expenditures Trends, 1975-1997.* Ottawa: Canadian Institute for Health Information, 1997.

that over $25 billion was spent on hospital services in Canada.

Cost control efforts in hospitals across Canada are of two general types, efforts to reduce hospital use, and efforts to reduce the duration and the cost of each hospital service provided (Dickinson 1994:116). As Armstrong and Armstrong (1996:86) maintain:

> Most hospitals treat acutely ill or injured patients. At these hospitals...-shortening stays, shifting to out - patient treatment, cutting back on beds and staff, contracting out and standardisation - are both widespread and mutually reinforcing. They also reinforce the medical model and can endanger patients. In hospitals that offer rehabilitation and long-term psychiatric services or extended care, similar strategies are also being used. In addition, governments are seeking to move people out of the institutions into other residential care facilities or into the community.

The political and economic processes of the fiscal crisis and subsequent cutbacks to the provision of health and mental health services in Canada "leave gaps to be filled by private or voluntary organizations or gaps within family or community (usually filled by women)" (Martin 1996:7).

Given these cutbacks to the provision of health and mental health services, how can the state expect women as primary family caregivers of the chronically mentally ill to cope under these crisis-like conditions with so few resources? How can the state expect these women to be effective caregivers under such conditions in which they are likely to incur health and mental health problems related to stress and fatigue? How can the state expect these women to manage the conflicting nature of mental health policy directives, the Canadian Charter of Rights and Freedoms, the Uniform Mental Health Act and provincial mental health legislation that exacerbates the challenges that they face? These are serious questions that concern women as primary family caregivers. the chronically mentally ill and society at large and should have been anticipated and addressed by the state prior to deinstitutionalization, the shift to community care and the design and implementation of current health and mental health policy and mental health legislation.

As Bolton (1997:A24) argues:

> In recent years, the government [in Canada] has closed down a number of facilities which offered specialized care to individuals suffering from psychiatric disorders. Reducing the number of psychiatric beds in order to save money is not only inhumane, it is false economics. The mentally disordered are merely shifted from one publicly funded organization (the hospitals) to another (welfare, the courts, jail et cetera). Moreover, the effect on relatives of the mentally disordered . . . is equally devastating.

Ironically, the state (Epp 1988:17) argues that "as chief caregivers of the chronically ill and principal 'health promoters' [and principal mental 'health promoters'] for their members, families (and in particular, women) need more recognition and support for their tasks." Further, "[a]t a certain point, family responsibility becomes society's responsibility, and caregivers need to be assured that they will not be expected to shoulder limitless burdens" (Epp 1988:17). Despite these empathetic assertions, the state does expect female family caregivers to shoulder limitless burdens since "a major problem with the implementation of deinstitutionalization has clearly been the failure to fund community programs at anything approaching adequate levels" (Scull 1985:549).

The state also maintains that "the protection and promotion of mental health should be a matter of compelling priority for every community in Canada" (Epp 1988:23) although it has failed to make mental health a compelling priority. Community-based services for the chronically mentally ill across Canada remain consistently "underfunded, uncoordinated and unequipped" (Gaudet 1994). To date the term "community" has yet to be clearly defined in health and mental health policy (Armstrong and Armstrong 1996:144). The term "community" as central to the notion of "community based care" in mental health policy often refers to private based care in contrast to public institutional facilities. Bryson and Mowbray (1981:263) critically note that "[m]inimization of public expenditure is a fundamental plank in conservative economic policy which is served by the use of 'community' to denote certain programs that involve a transfer of responsibilities to the local (community) level-which, in practice and just incidentally, usually means to women. The 'spray-on' application of community to such strategies might be best seen as a sugar coating for a bitter pill..."

Most women as primary family caregivers of the chronically mentally ill find "the bitter pill" of the transfer of responsibilities of care and the burdens of caregiving to be ones that they cannot absorb in that they are already overburdened with paid part or full time employment as well as unpaid domestic labour. Thus, significant contradictions exist between the public interests of the state and the private interests of these women. According to Armstrong (1994:99), several time-budget studies (Clark and Harvey, 1976; Haddad and Lam, 1989; Luxton, 1980; Harvey, Marshall and Frederick, 1991; Meissner et al. 1975; Michelson, 1985; Ng and Ramirez, 1981; Sinclair and Felt, 1992) indicate that it is women who regularly prepare meals, do laundry, clean the house and maintain social contacts. While there is some variation across class, cultural and regional groups in these studies, the overall pattern on the division of labour in the home is remarkably similar in all groups from coast to coast. As Armstrong (1994:99) maintains:

> Women still do such work even if they have another job in the labour force. They simply reduce or eliminate their leisure time and do some tasks less often. In dual-earner

> households with small children, women contribute almost 30 hours a week more than fathers to household demands. It is mainly women's cooking, laundry, cleaning and emotional support work that increases when people are sent closer to home; mot primarily the men's yard and car work or their repair tasks.

Hence '[f] ew [women] have the time and even fewer have the skills to provide the kinds of long-term care required by those who are deinstitutionalized"[18] (Armstrong and Armstrong 1996:88). As a result, care of the chronically mentally ill may be inadequate or dangerous.[19]

Evidently, as Armstrong and Armstrong argue from a feminist political economy perspective, developments such as the fiscal crisis in Canada and subsequent cutbacks to the provision of health and mental health services have enormous implications for households in general and for women as primary caregivers in particular. According to Armstrong and Armstrong (1996:7) 'the [O'Connor] theory needs to be revised to include a third role for the state. In addition to encouraging accumulation and legitimation, states also play a critical part in structuring what is provided for publicly in the market and privately in households, in who does the work in these spheres and in how it is done." With the shift to community care and bringing chronically mentally ill patients "closer to home", the state is playing a third role overlooked by the O'Connor theory in structuring what care and mental health care is provided for publicly in the market and privately in households, in who does the work in these spheres (typically women) and how the work is done (Armstrong and Armstrong 1996). Beneath the

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[18] Ineffective care of the chronically mentally ill increases the long-term costs not only for the care recipient but also for the state that has to deal with the consequences in the form of the costs of transinstitutionalization (Porporino and Motiuk 1994).

[19] In addition, according to Gaudet (1994:5) "Mainstream health services and welfare services [in the community], which operate independently of each other, do not respond well to the special needs of the most severely mentally disordered persons, whose medical and social needs tend to be closely interconnected and intensive."

veneer of community care and bringing patients "closer to home" lies the misery of women as primary family caregivers of the chronically mentally ill that remains a private misery, with potentially long-term social costs that are very difficult to quantify (Arnhoff 1986).

These women's private misery and their personal "troubles" that Mills (1959:8) explains as "a private matter: values cherished by an individual are felt by him [her] to be threatened" are managed by their governance of chronically mentally ill family members[20] as a complex form of power while managing public "issues". These public "issues" managed by women include: deinstitutionalization, cutbacks to mental health services and the contradictory liberal rights and medical model discourses embedded within and between mental health policy and legislation. Their governance of these issues often "involves a crisis in institutional arrangements, and often too it involves what Marxists call 'contradictions' or 'antagonisms.' (Mills 1959: 8)

Hence, governance is an analytical tool that enhances the feminist political economy framework in that it provides the feminist researcher with a purposeful analytical model of inquiry to observe and examine structure and female family caregivers' agency and power in that: 1) women as primary family caregivers of the chronically mentally ill are disadvantaged, but not helpless in that they exercise a complex form of power over chronically mentally ill family members in two sites, both the private and public sphere in order to manage the problems, issues, tensions and contradictions that are present at both the micro and macro level and 2) this complex form of power is constantly being

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[20] The values that are cherished by women as primary family caregivers of the chronically mentally ill are those that are part of civil society. The values of the sphere of basic humanity are beliefs in citizenship rights that are increasingly being threatened with the decline of the welfare state.

negotiated and altered within constraints and resistance. As Foucault contends "[w]here there is power, there is resistance"(Foucault 1978:95) and "there are no relations of power without resistances; the latter are all the more real and effective because they are formed right at the point where relations of power are exercised" (Foucault 1980:142).

Further, consistent with Foucault (1980:198) I contend that governance as a complex form of power is relational in that "[i]n reality power means relations, a more-or-less organized, hierarchical, coordinated cluster of relations." Hence, female family caregiver governance of the chronically mentally ill is relational. As Gordon et al. (1996:xiii) note "[c]aring is not dependent, on what I do to you, but on what I do and how you receive or respond to it. The quality of any caregiving relationship, furthermore, depends not solely on the skills and receptivity of the caregiver but on the receptivity and response of the one cared for." Gordon et al. (1996:xiii) also explain that "[t]iming, context, and the ability to perceive a range of human possibilities [are important qualities of any caregiving relationship] and in turn, dependent on a social context that supports it."

This study addresses the governance of the chronically mentally ill by female family caregivers within a feminist political economy framework. What are the problems, issues and tensions created for these women by the macro caregiving context? What is the nature of the governance by these women of their chronically mentally ill family members in managing the contradictions in their roles as primary family caregivers and as state designated mental health promoters and the resistance of their chronically mentally ill family members to this governance? These are the questions that the analysis of my semi-structured in-depth interviews with 15 female family caregivers of chronic manic depressives and schizoaffectives in this thesis endeavours to answer. Chapter 3 will proceed with the methodological orientation of this study.

3.0 CHAPTER THREE: METHODOLOGY

This research consists of a case-study involving in-depth, semi-structured individual interviews with a purposive sample of 15 female family caregivers of chronic manic depressives and schizoaffectives (see Appendix A - Study Questionnaire). The case-study was designed to examine: 1) the problems, issues and tensions created for women as primary family caregivers of eight chronic manic depressive family members and nine chronic manic depressive family members with schizophrenic tendencies (or schizoaffectives) by the macro caregiving context and 2) the governance by female family caregivers of eight chronic manic depressive family members and nine chronic manic depressive family members with schizophrenic tendencies (or schizoaffectives) as a complex form of power used to manage the contradictions in their roles as primary family caregivers and as state designated mental health promoters and the resistance of family members. For the purposes of this thesis, the term "governance" is defined in its broadest sense to include "the institutions, procedures, analyses, and reflections, the calculations and tactics that allow the exercise of this very specific albeit complex form of power" (Foucault 1991:102). Further, for the purposes of this thesis, the term "resistance" is defined as to "strive against, oppose, try to impede, refuse to comply with" (Sykes 1984:886).

The decision to interview women in this study was based on consistent findings that report that they "are the overwhelming majority of care-givers in the home and in the community" (Armstrong 1994:94). Further, female family caregivers of the chronically mentally ill represent a segment of society who are not often listened to or heard. The second characteristic of subjects interviewed in this study are their roles as primary caregivers. These subjects are the people who come from the "underside" of deinstitutionalization and community care, people whose opinions on these phenomena are seldom sought out and often dismissed. Who understands best what it means to be caregivers to family members with chronic mental illness? Who could best judge if they have been given a say in the mental health policy and legislation that affects them, their family members and society at large? Who are the experts? As sociologists, if we want to understand the reality of deinstitutionalization, community care and family caregiving of the chronically mentally ill, it is best to listen to those who do the work.

The topic of inquiry chosen by the researcher is a direct reflection of the academic and social predispositions of the researcher As White (1994:116) argues "[t]he results are the consequence of the topic of inquiry and that does reflect our social and humanist bias." We are deceiving ourselves as social scientists if we believe that we are not as human as the people we study (Myrdal 1969). Indeed, as White (1994:116) maintains "[w]e are scholars with a social conscience. That is why we chose to study what we did. As C. Wright Mills noted 'there is a politics of truth' and the choice of what issues to do research on is a political act."

Even though feminist researchers try to study women from the standpoint of women and generally have access to women's settings, the women that researchers study do not always trust them (Reinharz 1992). This was a dilemma for the researcher as a feminist. Further, the caregivers were distrustful of professionals. Thus, prior to the interview, I disclosed to each subject that I, too, have experienced primary family caregiving for two chronic manic depressive family members. As Oakley (1981:41) writes, "the goal of finding out about people through interviewing is best achieved when the relationship of interviewer and interviewee is non-hierarchical and when the interviewer is prepared to invest his or her personal identity in the relationship." Further, as Lafond (1994:74) argues '[m]oving beyond our trusted friends and acquaintances in an attempt to challenge the stigma of mental illness is a worthy task."

3.1 Sampling

The subjects in this study represent a purposive sample of 12 current and three former (one recently divorced from their schizoaffective family member, one recently separated from their manic depressive family member and one recently deceased schizoaffective family member) caregivers of chronic manic depressives and schizoaffectives. The purposive sample represented 15 women from a total of 22 self-identified volunteers who responded to interview advertisements (see Appendix B - Interview Advertisement) placed at support groups for those with mental illness and their family members and at social service and disability related agencies across Ottawa. Unfortunately, during the first two weeks of January 1997 (approximately three weeks prior to the interview schedule), two self-identified volunteers advised the researcher that they were unable to participate in the study due to the present stress in their lives of managing chronic mental illness in their respective families. Five self-identified volunteers were interviewed in the pre-test but were not included in the final study.

The methodology of this study avoided purposive samples obtained exclusively from support group members. First, the support group families are not representative of all families of the mentally ill (Maurin and Boyd 1990; Jones and Jones 1994:76). Support group participants are generally white, married, better educated, more financially advantaged, and more supportive of their disabled family member than the majority of family members of the mentally ill (Jones and Jones 1994:76). Thus, '[t]o get a diverse sample, Hanna purposely shied away from support groups which she says tend to be white and middle class" (Dey 1997:22). Given this, the list of subjects represented a cross-section of caregivers.

All subjects have identified their family member as having been professionally diagnosed according to the official nomenclature of the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (1994) (currently termed DSM-IV), as manic depressive or schizoaffective. The subjects ranged in age from 20 to 69 years with a mean of 38 years of age. Two subjects identified themselves as having been professionally diagnosed according to the official nomenclature of the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (1994) (currently termed DSM-IV) with manic depression. All subjects and their chronically mentally family members are members of different kinds of families that include: nuclear, extended, blended, childless, lone-parent and Common Law marriages (The Vanier Institute of the Family 1991).

The chronically mentally ill family members ranged in age from 22 to 68 years with a mean of 43 years of age. Nine family members (seven females and two males) were identified as having been professionally diagnosed according to the official nomenclature of the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (1994) (currently termed DSM-IV), with schizoaffective disorder. Eight family members (two females and six males) were identified as having been professionally diagnosed according to the official nomenclature of the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (1994) (currently termed DSM-IV) with manic depression.

3.2 Data Collection

All research material was collected and analyzed for this study through a feminist political economy perspective with the use of Foucault's notion of governance. This study utilized a feminist qualitative research methodology of in-depth semi-structured interviews. According to White (1994:112), "[t]here are few issues that are of more importance to the scholar than the selection of methodologies for scientific investigation." Further, the adequacy of any research methodology depends on the purpose of the research and the questions that are being asked by the researcher (Seidman 1993). As Bertaux (1981) argues, it is wrong to apply the methods of the natural sciences such as experimental and quantitative to all situations in the social sciences.

Bertaux (1981) also maintains that the subjects of inquiry in the social sciences can talk and think and if they are given a chance to think freely, subjects appear to know a lot about what is going on. Further, I support White's (1994:113) contention that:

> When depth and richness in the research findings are the goal, or the purpose is to find the direction of the underlying processes, then qualitative methods such as those used in this study are the most appropriate

> (Marshall and Rossman 1989). We would argue that uncovering experiences is an important method for gaining data. The challenge is to get people to relate their experiences and to develop a method of analyzing the information.

Finally, at the root of in-depth interviewing is a research interest in understanding the experience of subjects and unravelling the meaning of that experience (Marshall and Rossman 1989).

Permission to conduct this study and to interview all subjects was granted to the researcher by Carleton University's Ethics Committee in November 1997 (see Appendix C - Carleton University Ethics Committee Clearance). A pre-test of the semi-structured questionnaire was conducted with five primary female family caregivers of chronic manic depressives who were not included in the final study. Prior to the interview, the subjects in the pre-test were introduced to the purpose of the study and the method used to guarantee confidentiality and anonymity. In addition, all subjects were told that they may choose not to answer any question at any time of the interview and may end the interview at any point should they wish to do so. All subjects chose to answer all questions and complete the interview in its entirety.

All subjects agreed to complete a letter of consent (see Appendix D - Letter of Consent) and were given a letter of thanks for participation (see Appendix E - A Post Interview Letter of Thanks from the Researcher) prior to the interview which outlined four community resources that assist family caregivers of the mentally ill and their family members in the Ontario and Quebec region and listed phone numbers of these community resources. The interviews were tape-recorded and the subjects were informed of this well in advance. Before the interviews started, subjects were asked to give a pseudonym to protect anonymity. With regard to confidentiality the researcher proposed to erase each interview tape the following day after the interview or return the tape to the subject on the following day. Although the subjects were asked to sign an informed consent form, the researcher has retained the signed consent forms in a securely locked cabinet until they are destroyed or returned after the thesis defence at the subjects' request. As a result of this pre-test, the researcher decided to re-order some of the questions and re-word other questions to make them more clear so as not to confuse the subjects in the final study.

Finally, the semi-structured interview questionnaire was designed. According to Reinharz (1992:18) "[t]he use of semi-structural interviews has become the *principal means* by which feminists have sought to achieve the active involvement of their respondents in the construction of data about their lives." This method is further defined by Reinharz (1992:18) as:

> ...a qualitative data-gathering technique. It differs from ethnography in not including long periods of researcher participation in the life of the interviewee and differs from survey research or structured interviewing by including free interaction between the researcher and interviewee. Survey research typically excludes, and interview research typically includes, opportunities for clarification and discussion. Open-ended interview research explores people's views of reality and allows the researcher to generate theory.

As Kelly (1994:81) maintains "it is virtually impossible to understand the complexities of human interactions using survey instruments. In general, doing so requires in-depth face-to-face interviews."

The researcher followed an interview schedule with the same semi-structured questions included in each interview. However, there were different clarification questions asked in each interview; a factor in the very rich and detailed nature of the data, the number of family members with chronic manic depression and/or schizoaffective disorder and the particular experiences that were shared. According to Armstrong (1994:93), "[t]his kind of research instrument, more than other types of research, allows those issues to surface that are considered to be important by the subjects at the same time as it permits the coverage of issues critical to researchers. In other words, the intrusion of the researcher is minimized precisely because the participants have more freedom to address issues as they choose."

The interviewer avoided the use of the completely unstructured interview which was found during pre-tests to confuse and/or intimidate respondents. Instead, semi-structured questions were used with "planned" and "floating" prompts to ensure "that data are collected for all of the categories and relationships that have been identified as important" (McCracken 1988:38). A variety of these prompts were employed to ensure that the issues were thoroughly addressed. All subjects chose to answer all questions and complete the interview in its entirety. After all 15 interviews were completed, the tapes were transcribed by an independent service that knew neither the identity of the caregiver or their family members. The transcriber was obliged to ensure that the tapes and transcripts of interviews were retained in a securely locked cabinet until completion and submission to the researcher (see Appendix F - Contractual Agreement with Transcriber).

For the researcher, ensuring activities of prolonged engagement and persistent observation is essential so that the qualitative research experience does not become a meaningless journey into another person's life. Similar to reliability and validity, trustworthiness ensures that the data can be believed. Prolonged engagement was used to assist the researcher in shaping the in-depth, semi-structured interview questionnaire with the subjects in this study for the purposes of sociological inquiry rather than for the exclusive purpose of ethnographic study. This prolonged engagement is the investment of sufficient time in order to achieve certain purposes such as learning the culture, testing for misinformation introduced by distortion, and building trust with subjects (Lincoln and Guba 1985). This was accomplished first and foremost through my own first-hand experiences as a participant observer in an Ottawa-based family support group for family members of persons with depression, manic depression and schizoaffective disorder that I have attended on a bi-monthly basis for 20 months. Through careful documentation and by watching, listening and asking questions at these support group meetings, female family members attending these support groups have indicated some of the relevant factors, processes and issues that deserve detailed and critical examination, description and explanation in this thesis. This was also accomplished through prolonged engagement with contacts in psychiatric hospitals, hospitals, community health centres, non-government agencies and law firms serving persons with disabilities, government agencies serving persons with disabilities and other community resource staffs in the Ontario and Quebec region. The researcher also familiarized herself with the subjects' journals of the manic and depressive episodes of their family members, the subjects' documentation of exchanges with their chronically mentally ill family members and/or health care professionals as well as any other relevant information that would prove useful when interviewing the subjects.

The purpose of persistent observation is to identify those characteristics and elements in the situation which are most relevant to the problem or issue that is being researched (Lincoln and Guba 1985). Common characteristics observed through prolonged engagement were formulated into themes which were explored and developed into the working hypotheses.

3.3 Data Analysis

The researcher reviewed all interview data to identify any salient points that particularly stood out as important themes. Themes from all 15 interviews were coded, compared and similarities were noted. In the analysis of these particular case-study results, comments by subjects fall into three categories. The typical comment is one that re-occurs and has no substantial refutation in other interviews. It is this kind of response that is the primary focus here. The unusual or atypical remark is one that is not repeated widely enough to be considered undeniably reflective of the interviews. Very few of these have been included, and then only offered as examples of more typical patterns. The third type is the comment that is clearly outside the main response group. It is reported only on rare occasions and is identified as outside of, or contradictory to, the bulk of respondents. This comment is similar to an outlier in quantitative data.

3.4 Methodological Limitations

The limitation of the semi-structured interviews of this study is the issue that the study depends primarily upon retrospective data, which presents two difficulties: subjects may repress events and may have difficulty recalling details of all episodes of their chronic manic depressive or schizoaffective family members. This was anticipated and identified with certain questions in the pre-test. Thus, to reduce these threats to validity, such questions were re-worded and asked in more than one manner in the interview. This was highly effective in overcoming these limitations. As well, methodological limitations lie in the fact that the study was conducted using a purposive sample of 15 subjects rather than a randomly selected sample of a larger number of subjects. However, as with Renzetti's (1992:13) subjects in her study involving interviews with abused lesbians, "it is doubtful that one could obtain a truly random sample of a group as hidden and highly stigmatized as battered lesbians" and this is also true of female family caregivers of the chronically mentally ill. Further with regards to the sample, as McCracken (1988:17) writes "the first principle is that less is more. It is more important to work longer, and with greater care, with a few people than more superficially with many of them. For many research projects, eight respondents will be perfectly sufficient." Chapter 4 will proceed with the study analysis.

4.0 CHAPTER FOUR: CASE STUDY ANALYSIS; FEMALE FAMILY CAREGIVERS OF CHRONIC MANIC DEPRESSIVES AND SCHIZOAFFECTIVES AND THE GOVERNANCE OF MADNESS

The semi-structured interview data with 15 female family caregivers of nine manic depressive family members and eight manic depressive family members with schizophrenic tendencies (schizoaffectives) in this study have been collected and analyzed from a feminist political economy perspective using Foucault's notion of governance. The interviews produced rich and eloquent descriptions of 1) the problems, issues and tensions created for women as primary family caregivers by the macro caregiving context and 2) the governance by female family caregivers of chronically mentally ill family members as a complex form of power used to manage the contradictions in their roles as primary family caregivers and as state designated mental health promoters and the resistance of family members. While I have arranged their responses to fit into an ordered framework of the following: 1) the never-ending burden that includes: caregiving, domestic and wage labour and, social isolation, stressed interpersonal relationships and stigma 2) crises and uncertainties that includes: abuse of care recipient, abuse of caregiver, alcohol and drug abuse and, a potential danger to themselves and/or others 3) exercising skill and its limits that includes: monitoring and controlling manic and depressive episodes, monitoring and controlling medical compliance, monitoring and controlling outpatient hospital treatment, monitoring and controlling hospitalization, monitoring and controlling medical file information and devaluing caregiver knowledge and 4) mutual help groups, I have abbreviated some for the sake of clarity and tried to let the women speak for themselves[21].

4.1 The Never-ending Burden

The majority of women in the study shoulder the never-ending burden of caregiving for family members with chronic mental illness while doing domestic and wage labour. None of the women in the study failed to mention the ongoing demands and tasks involved as primary family caregivers of their family members and the problems, issues and tensions around the never-ending burden of caregiving, domestic and wage labour and, social isolation, stressed interpersonal relationships and stigma.

Caregiving, Domestic and Wage Labour

Many women in the study reported bearing the burden of three jobs: of caregiving for their chronically mentally ill family members, unpaid household labour in the home and of segregation into low paid, routine women's labour. Women reported ongoing demands and tasks around bearing this burden such as: 1) working all day in a daycare and going home to do all of the cooking and housework, often cleaning paint from the sink and from dishes and cleaning cat urine and feces from the floor during a family member's depressive episodes and substance abuse 2) working all day in the home as a self-employed consultant, doing a substantial share of the housework and supervising the manic and depressive episodes of a family member 3) working all day in the home as a housewife while supervising the manic and depressive episodes of two family members and 4) going to school all day and going home to do a substantial share of the housework, while trying

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[21] In order to distinguish the questions of the researcher from the responses of the subjects, the researcher's questions are indicated with a query notation.

to be quiet and other days, being required to miss school entirely to serve as a translator between the doctor and a family member.

"Sheila",[22] a 24 year-old former daycare worker with cerebral palsy and caregiver of her unemployed 41 year-old chronic manic depressive ex-common law husband who repeatedly refused treatment for his chronic mental illness and abused alcohol, drugs and sniffed paint, explained the strain of juggling caregiving, domestic and wage labour:

> ...I have to take the bus home [from work], sometimes he'd be very very nice, or mope around and be the easiest person ever. One day there was nothing, nothing, nothing done. I came home and it was a total disaster. The dishes weren't done, the meal wasn't cooked, nothing. I had to spend time at home working, and I had mouths to feed. Well, I'm not supposed to be working for all that much period cause I get exhausted by the end of the day [from cerebral palsy] and there was no laundry done, so I had to do that. Of course I had to fill up the bath with a jug full of water, because there was no water running to the apartment. So it was just...sometimes it was really strange, sometimes it was hard....there would be paint in the kitchen sink, all the time, or on my dishes and I'd ask him about it and he wouldn't remember how it got there. He would just not know. I mean I'd ask him, "Didn't you change the cat's litter?" "No." [he would respond] "Why not?" "Oh because I didn't feel like it or I didn't want to, can you change it...later...okay?" So, then I'd come home and there'd be poop or pee [from the cat] all over the floor.

"Maureen", a 36 year-old home based self-employed consultant and caregiver of a 46 year-old chronic manic depressive husband, described the never-ending burden of supervising the manic and depressive episodes of her family member in that her "number one" task was a "*combination of encouragement and reality check. It's something*

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[22] In this chapter, all subjects and their caregivers are assigned a pseudonym to protect anonymity. The pseudonym and a more detailed description of the caregivers and their family members are provided to the reader the first time they are discussed in this chapter, and at any point afterward they are referred to only by their pseudonym.

we do over and over and over again." Further she explained, " *Finding out how he is feeling. If I notice he's feeling bad, him resting and not doing much work... and if he's feeling discouraged about it, then encouraging him, finding reasons to explain why he might be feeling low after seven days or strenuous activity. Take a breather, or something like that, or just clarifying the level of the symptom, if its really that serious or not. If there is anything I can do.* " During the manic and depressive episodes of her family member she would do a more substantial share of the housework as she added, *"then I would say secondarily, is if he's feeling low for several days in a row, then I will do a much more substantial share of the housework."*

Similarly, "Eleanor", a 48 year-old housewife and caregiver of a 24 year-old chronic manic depressive son and a 22 year-old chronic manic depressive son, described supervising the manic and depressive episodes of her two family members as "*[s]itting up sometimes all night, or all day, a couple of days talking to them [two sons with chronic manic depression] they get bad headaches*" and "*trying to keep it relatively calm at home*" and dealing with their erratic behavior while trying to be supportive:

> ...sometimes there'd be problems at school, writing notes or skip classes. Friends wondering what the heck is going on because of behavior problems...once I had to call the police because Jake and Cory got into a big fight, a physical fight. I'm trying to think, just trying to be supportive, being there for them to talk to, keeping a close eye on how they're feeling.

"Lynda", a 26-year old university student and caregiver of a 48 year-old female chronic manic depressive mother with schizophrenic tendencies, recalled the never-ending burden of performing household tasks and the demands as a primary family caregiver from early childhood as a schoolgirl:

> When we [she and her sister] came home after school we were not allowed to go outside and play with our friends, we had to come home immediately, the T.V. could not be on, the house had to be spic and span, we had to be quiet, silent...we were supposed to be silent, out of the way and so we were taught to cook and clean. I was cooking at the age of 6 or 7, making meals over the stove, doing it wrong...getting a slap across the face by my dad.

Further, she would be required to miss school entirely to serve as a translator between the doctor and her mother who would insist "*don't go to school today because I want to go to the doctor's, you have to help me translate cause I can't speak English*" and "*this was going on for 15-16 years*"

For these women there can be no holiday from this never-ending burden. Maureen and Janice reported: 1) trying to supervise the manic episode of a family member while on a sightseeing train during a vacation and 2) trying to supervise the manic episode of a family member while unexpectedly off medication during a holiday. Maureen described trying to supervise her husband's unexpected manic episode while they were on vacation:

> ...he was so high and he became so high near the end, we were alone on a sightseeing train and he wanted to get up and started walking up and down the cabin, and I just said to him, "If you don't sit down, beside me right now in this seat, then the minute we get back to town, we're packing our bags, we're going to the airport and we're going back to Ottawa on the first plane that could go," and that was it.
>
> ***Query: And how did he respond?***
>
> He was really angry, he sat down with great difficulty.

"Janice", a 42 year-old business owner and operator and caregiver of a 41 year-old manic depressive husband also described trying to supervise an unexpected manic episode after his decision to come off of his medication before going on holidays without her knowledge of his decision to do so:

> ...he was off the Lithium... we were in the hotel, I said that I was going to lie down for a rest and would he let me know if he was going to go out, so I could go with him. He never let me know and he went off and left me and then he came back and bought all these things for himself... like a raft to go in the ocean with all sorts of equipment. He said, "I've been feeling so much better. Now I've come off it, I have so much more energy." And I said, "Well, I've noticed that you've had a bit more energy and you seem a lot more enthused but there's something else in your personality. It's kind of an aggressive thing." So he listened to what I said but then he started going into a sort of depression after we came back from our holidays. Then he started to realize what had happened was that his body started to respond to the chemical changes and he realized that he was heading to a depression and then it started to get bad and he started taking Lithium...

Based on these women's narratives, it is clear that the responsibilities and never-ending burdens of caregiving are difficult to absorb. Many of these women are already overburdened with paid part or full time employment as well as unpaid domestic labour and reported additional social isolation, stressed interpersonal relationships and stigma that accompanies this never-ending burden.

Social Isolation, Stressed Interpersonal Relationships and Stigma

All women in the study reported experiences of social isolation, stressed interpersonal relationships and stigma from friends, neighbors and relatives. Women reported social isolation, stressed interpersonal relationships and stigma from friends, neighbors and relatives such as: 1) not being able to receive friends in the home for fear of her two family member's manic and depressive episodes 2) not being able to leave the home because of household duties that needed to be performed for the family member during manic and depressive episodes 3) not being able to receive friends in the home because of past behavior of the family member during manic and depressive episodes and the consequential labeling of the family member and stigmatization of mental illness in the family 4) not being able to leave home for fear of two family members harming themselves and/or other family members or damaging the home and for fear of what the neighbours might hear and/or see during their manic and depressive episodes and the consequential labeling of the family members and stigmatization of mental illness in the family and 5) the loss of friends because of disclosure of the mental illness of the family member and the consequential labeling and stigmatization of mental illness in the family.

"Gail", a 44 year-old unemployed person with a disability, caregiver of a 68 year-old chronic manic depressive mother and 40 year-old chronic manic depressive brother described the social isolation of the never-ending burden of caregiving for two family members as *"I just don't have a life, my life is totally hinged on mother and brother….there are very few [friends] now because of my situation at home."* Further, she explained not being able to receive friends in the home for fear of her two family members manic and depressive episodes:

> I don't have friends over because you just never know if mother or John are going to blow up or an embarrassment is going to occur. You know, that's going to blow it for you. So, you just don't have people over anymore. My times of going out are very limited. If I do go out it's only for short periods of time, that sort of thing.

Lynda recalled the painful social isolation of growing up as a child of a mother with chronic schizoaffective disorder and not being able to leave the home because of household duties that needed to be performed for her mother during manic and depressive episodes:

> Well first of all, right off the bat, I had to spend a lot of time in the home doing a lot, parenting, taking on the role of a parent, so therefore your needs or my needs are secondary. I didn't have a lot of friends. I had a few close friends. I seldom went out. I guess I was really just a homebody.

"Tracey", a 20 year-old high school student and caregiver of a 48 year-old chronic manic depressive mother with schizophrenic tendencies, recalled the painful stigma and social isolation of being called the "school freak" as a child. Tracey also recalled not being able to receive friends in the home because of past behavior of her mother during manic and depressive episodes, the consequential labeling of her mother and the stigmatization of mental illness in the family:

> ...when I was a child, I had no friends. I couldn't bring my friends home because my mom would yell at them, and I did bring my friends home and my mom did yell at them, and I was known at school as the school freak because of my mother. I was the only five-year-old with no friends. I had one friend. I went to her house, and that was about it. She came over sometimes. She was the closest thing I had to a friend. I had her as a friend until I was about eight or nine, and my mom got worse by then.

Eleanor reported her experiences of social isolation, stressed interpersonal relationships and stigma from friends, neighbors and relatives as a caregiver of two chronic manic depressive family members and not being able to leave home for fear that they would harm themselves and/or other family members or damage the home. Eleanor also reported fear of what the neighbours might hear and/or see during their manic and depressive episodes, the consequential labeling of the family members and stigmatization of mental illness in the family:

> I didn't have a life. I just stayed home most of the time cause I was afraid to leave the house...because of what might happen while I was gone, what they might say or do to their siblings or what they might do to themselves or the house. What would go on, what the neighbors would hear or see or whatever. I had to go to church, I couldn't give that up, it was kind of my salvation for a long time. So, I didn't say too much even to the Minister but at least my faith helped. Sometimes I felt that was the only thing I had.

Janice reported the social isolation, stressed interpersonal relationships and stigma and the loss of friends because of the disclosure of her husband's manic depression, the consequential labeling and stigmatization of mental illness in the family in that "*[s]ome friends have cut him off*" and:

> ...one of my friends that I was friendly with, she did eventually learn that he had manic depression and she repeated it to some other friends that I had in Toronto and I felt that there was some distance there because of it. I think through the years as we've gotten older everybody struggles and you realize that life is not that easy so it has affected the friendships.

These women quickly learn that there is little community in community care and find themselves faced with social isolation, stressed interpersonal relationships and stigma as a result of others responses to the disclosure of their family members manic depression or schizoaffective disorder, responses to the behavior of chronic manic depressive and schizoaffective family members and the demands that they face as caregivers that require that they put the needs and wishes of their family members before themselves. These women also reported high levels of burnout or emotional exhaustion, depersonalisation, and reduced personal accomplishment that accompanies the social isolation, stressed interpersonal relationship and stigma that they face. Thus, "[w]hen caring ceases to be voluntary but rather becomes a necessary and never-ending burden, violence can result."(Armstrong and Armstrong 1996:142)

4.2 Crises and Uncertainties

None of the women in the study failed to mention the crises and uncertainties involved in their roles as primary family caregivers and state designated mental health promoters that include: abuse of care recipient, abuse of caregiver, alcohol and drug abuse and, a potential danger to themselves and/or others.

Abuse of Care Recipient

Over half of all of the women in the study reported that they had abused their care recipients from the frustration of caregiving and frustration with their family members frequent manic and depressive episodes and refusal to comply with medical treatment. These women reported physically and verbally abusing their family members. Tracey reported frustration in dealing with her mother's frequent manic and depressive episodes and her refusal to comply with medical treatment for schizoaffective disorder and revealed that she hit her mother several times:

> I hit my mom a couple of times. The last time I hit her, I was 15 or 16. She threatened to charge me, and I'd never do that again. Even if she did provoke me, I would never do it again because it's not worth it. She was paranoid. She thought I was getting my friends to laugh at her, gang up against her and humiliate her. She thought that I set her up to be humiliated in front of my friends, and it was a coincidence, that's all what happened. It was a bit of a coincidence that my friends were there at the same time she came to my house to pick me up. She argued with me for an hour in the car, and I took my hand sideways and whacked her arm and I gave her a pretty nice bruise. She has circulation problems...she bruises

pretty easily.

"Monica", a 24 year-old unemployed person and caregiver of a 24 year-old female chronic manic depressive sister with schizophrenic tendencies also reported frustration in dealing with her sister's frequent manic and depressive episodes and her refusal to comply with medical treatment for schizoaffective disorder reported that she pushed, punched and grabbed her sister and revealed that "*[s]ometimes when she was in her manic phase we would both physically push or punch or, I would grab her hand. Sometimes I would grab her, I would yell at her sometimes.*"

"Diane", a 56 year-old teacher and caregiver of a 29 year-old chronic manic depressive daughter with schizophrenic tendencies reported frustration with her frequent manic and depressive episodes and her refusal to comply with medical treatment for schizoaffective disorder and revealed that she verbally abused her daughter:

> ...when I was extremely exhausted and extremely angry I said something like "I'm sorry you were born" or something like that. I did it very rarely, it is a horrible thing to say, that understandable with the stress I had. I said it, once in four years and certainly I apologized for it and she knew the circumstances that we were through... very severe, hard times. She never holds anything against me and I never hold anything against her. I was seriously stressed. What can you expect?

The frequent episodes of family members who refuse to comply with medical treatment also leaves many of their caregivers vulnerable to abuse that perpetuates a cycle of violence.

Abuse of Caregiver

The majority of women in the study reported being abused by their family members with frequent manic and depressive episodes who refused to comply with medical treatment. These women reported that they had been verbally, physically, psychologically and sexually abused by family members. 'Nicole", a 50 year-old unemployed person and caregiver of her 57 year-old chronic manic depressive ex-husband with schizophrenic tendencies who refused medical treatment for his chronic mental illness reported that he withheld money for necessities, verbally harassed and pushed her, psychologically abused her, brutally killed her farm animals and withheld sex:

> In his severe high, he wouldn't give me a cent. In his severe low, he still gave me no money. This lasted three years... '94, '95, '96...the abuse was bad. A lot of verbal abuse. He would try to pick an argument and I'd realize that he was trying to pick a fight and so I would walk away and not say anything.
> ***Query: How did he respond to this?***
> He would back off. Once, though when he was at the end of his manic high in the end of June 1992 he lost control and shook me and pushed me violently into the kitchen wall. I was hysterical and I told him I was calling the police. I told him it was physical abuse.
> ***Query: Any other kind of abuse?***
> Yes, once I bought a cow in 1975. I paid $500 for it. Just because the cow couldn't have calves, he slaughtered it. He didn't ask my permission. He just cut her head off and put it on the front fence. He just killed and butchered her and put her in the freezer to eat in the winter. It was my cow and not his. He said she couldn't have calves so we had to do something with her. He said, twice he tried to put her in the truck to sell her, but twice she jumped out.
> ***Query: Any other form of abuse?***
> Yes, emotional. I knew I had to have my horse put down in 1990. I asked my neighbor to put him down by shooting her by rifle. The animal doctor said it was faster to shoot an animal than with a needle. I told my neighbor when I was ready I'd call him and make an arrangement because I wanted to say goodbye to my horse and take some pictures. I had this horse since she was three months old to 18 years old. She was like my child. I didn't want her to leave the farm, I wanted her to be buried on the farm. However, my husband wanted it his way. Paul did it when I took my dad to the hospital. He just killed my horse. I couldn't believe that they killed my horse without telling me. I gave him a tongue lashing. He had Terry, the neighbor, shoot the horse. Actually, he had some men come and pick her up afterwards. I got on the phone with these men and gave them hell. I told them I wanted my horse back and I wanted her back now. I told them that they had no right

> to pick up my horse from Paul. I was the horse's owner, not Paul. They had deboned the horse and skinned it. They used the meat for dog's food. I got off the phone and told Paul that he was a fucking bastard and that I had the horse for 18 years, I raised her, I trained her, I looked after her and I spent time in the stable when she was sick, they deboned her. I said, "The horse is now dog food."
> ***Query: Any other abuse?***
> Yes, sexual. During the low, there was no sex at all. He slept with his back to me.

"Amanda", a 31 year-old business owner and operator, and caregiver of her 59 year-old chronic manic depressive mother with schizophrenic tendencies recalled how her mother, who also refused medical treatment for her chronic mental illness, threw cutlery and darted knives and forks into the wall and threw the cutlery drawer at her:

> She would throw knives and forks...
> ***Query: Where? What happened?***
> Well, that kitchen wall got very...
> ***Query: How?***
> No one would ever talk about it. There would be holes and then my dad would come along and fill them with putty.
> ***Query: How would she do that? What happened? Were you eating?***
> I don't know, just...yeah...we would be eating and we would put our elbows on the table or we picked the fork up with the wrong hand, or...and one day, I remember, she just picked the whole knife and fork drawer and just whipped it at us.
> ***Query: But how would there be holes on the wall?***
> There would be holes on the walls from her stabbing them into the wall. My father would fill them with putty, so for years, even up to the time I was 18, my parents could never have anyone in the house anyway, but my father would putty [the holes], or whatever, and you could see it. The kitchen wall was off white. It was a constant reminder every time you walked in the kitchen.

Tracey recalled how her mother who refused medical treatment for her chronic mental illness broke her belongings on her dresser with a wooden spoon:

> She'd go through moods. She would get upset, and violent. She broke a few things in the house. She broke some of my things.

> When I was about eight or nine, she used to come into my bedroom with a wooden spoon. There was stuff all over my dresser. She'd take it, swing it around, knock all my toys on the floor. Sometimes things broke. She would make me clean it up, of course, and she'd be sure that I did clean it up. I'd listen, because I knew if I didn't get out of her way, she'd hit me.

Monica described how her sister who refused medical treatment for her chronic mental illness psychologically taunted her about meeting their birth mother and physically attacked her:

> She keeps making these connections with the bible, gets messages on the radio. It doesn't quite add up like she's got bigger connections on the TV and the radio. She'll make up something and it gets really out of hand. She'll say she met our birth mother. I tell her it's impossible. She'll say she knows our birth mother, she's met her and I say, "Give me a break." Then I say, "Okay what did you do today with her?" She says, "It kind of hurts, it kind of hurts. Leave me alone!" and I say, "Can we contact her?" She says "No... don't ask any questions." She goes on and on. She thinks we're laughing at her.
> ***Query: When... what do you say or do?***
> I started to smirk because I think it's kind of funny. She started to attack me. She fired off at me.

Eleanor described how her sons who both refused medical treatment for their chronic mental illness pushed and hit her:

> Physically 2 or 3 times he pushed me, once I fell into the corner of the chair and he cracked my ribs.... it was one of these bad episodes, whatever. Another time I was mad at him for something and I got annoyed, I went to... I was going towards him to talk to him but he got this scared animal look on his face and put his feet up and he pushed his feet out and hit me in the stomach and that threw me off.
> ***Query: Do you know how old he was? With these two different episodes?***
> 14, it was about the worse time, both.
> ***Query: What did you say or do when he did this?***
> Well, he was really shocked at what happened to me, but it hurt. It physically hurt and the incident when I fell, he kicked me in the stomach and I fell there was a kind of dead silence for all the kids

> who were there, and then he said "oh mum, I'm so sorry."
> ***Query: And how'd you respond to that?***
> Well I could hardly breathe so I said, "I'll be okay, just leave me alone."
> ***Query: And the other episodes?***
> Well you just kind of pick yourself up and you walk away.
> ***Query: What about Cory?***
> I think once he shoved me, that's it.

These women that abuse their care recipients and experience abuse from care recipients are often caught in cycles of violence perpetuated by the frequent manic and depressive episodes of their family members, their refusal to comply with medical treatment and the unpredictability of harm to themselves and/or others that often accompany these episodes.

Alcohol and Drug Abuse

Many of the women in the study reported that their family members abused drugs and/or alcohol and that they also refused to comply with medical treatment for their chronic mental illness that served only to exacerbate their manic and depressive episodes. Sheila, whose ex-common law husband refused medical treatment for his chronic mental illness and abused drugs, reportedly asked him "*why he couldn't get off the drugs first and go see his doctor, get help, but it was always the same story. Well later, when the baby comes. Then the baby was here and he wouldn't go. So then once the baby was here, he wouldn't go, he wouldn't go period.*" Further, she reported that he abused alcohol:

> He came home one night, his breath smelled, with this smirk on his face, grinning and I wanted to wipe that smirk off his face because he hadn't been home in about two weeks now and it was a grin that I couldn't bear, I just took him and I slapped his face and tried to knock it out of him and I said, "Go to detox because, if you don't I'm calling the cops to come pick you up for the night cause I don't

want to see you." He ended up in detox.

Nicole, whose ex-husband refused medical treatment for his chronic mental illness and abused alcohol reported that, "*When he is low, he is quiet, won't express himself. He looks down and drinks a lot....A lot of mood swings, nice to you in the morning but three hours later, he was rude.*" Further she explained that he abused drugs "*He ...smokes cigarettes and pot [during a manic episode] which he never does any other time. He really wants to be a real cowboy. He put an ad in the papers looking for women during his high in January, February and March of 1996. The ad said, that he was single looking for someone special and that he was physically fit and financially secure, a non-smoker. Once, I found a woman's underpants in my bed.*" These women have to contend with the frequent manic and depressive episodes of their family members, their refusal to comply with medical treatment, their alcohol and/or drug abuse and the potential danger to themselves and/or others that often accompany these episodes, and as the majority of caregivers reported, often leads to arrest.

A Potential Danger to Themselves and/or Others

The majority of women in the study reported that the manic and depressive episodes of their chronic manic depressive and schizoaffective family members often included behavior that was a potential danger to oneself and/or others with one schizoaffective family member committing suicide during a depressive episode. Women reported behavior that was a potential danger to oneself and/or others during manic and depressive episodes such as: 1) a family member that had tried to rob a restaurant 2) a family member that discharged a gun through the ceiling of the house and drove the car into the garage door and 3) a family member that went walking through the woods in the winter in a nightgown. Further, one woman reported that she hid sharp objects for fear that her sons would use it on themselves and/or on other family members and another woman reported that her father-in-law stood at the house window ready to discharge a rifle pointed out the window at helicopters

"Ingrid", a 69 year-old retiree and caregiver of a 42 year-old chronic manic depressive daughter with schizophrenic tendencies who refused medical treatment for her chronic mental illness reported that when her daughter left home temporarily to stay with some friends she tried to rob a restaurant during a manic episode:

> ...in '93, '94. She was living in Mont Clarmont with Karen and Bryan at the time. She was out of the house, went into Clara's Roasted Chicken and Ribs, said that she had a gun and they had to evacuate all the people from Clara's. The police came and she didn't have a gun. She didn't. She did spend the night in jail...a few hours, I think. Again, she wasn't staying at my place at the time. Then that was over and very luckily, her brother-in-law Kevin, my little daughter's husband, a well known lawyer....he did go to a court house a few times and he got it quashed...

Amanda whose mother refused medical treatment for her chronic mental illness described how her mother during a manic episode discharged a firearm through the ceiling of the family home "*[s]he shot the gun through the ceiling. I was in bed. Next morning, everybody woke up, there was a big hole in the roof, but no one would talk about it.*" She recalled how her mother during another manic episode " *drove the car into the garage door once*" and also recalled her mother's frequent "*death walks*" during depressive episodes:

> She went out a couple of times in the winter, she went walking in the woods. We didn't know she was gone...she usually came back within half an hour or the police brought her home. She was just in her nightgown. She always said she was gone for a "death walk" and never...she would never come back and it would always be winter...

Eleanor, whose sons refused medical treatment for their chronic mental illness stated that she hid sharp objects for fear that her sons would use it on themselves and/or on other family members during manic and depressive episodes as she explained she "*tried to hide anything that was sharp. Cause I was afraid somebody might come after themselves or somebody with it.*"

"Sophie", a 24 year-old college student and caregiver of a 42 year-old chronic manic depressive father-in-law who refused medical treatment for his chronic mental illness reported that her father-in-law stood at the house window ready to discharge a rifle pointed out at the helicopters during a manic episode:

> He [chronic manic depressive father-in-law with schizophrenic tendencies] would be feeling paranoid. Paranoid. He would think that the phone line was bugged. I know that one day he came home and he erased every movie that he recorded and every game that we copied on the computer. He would look at the window with his rifle, look outside at any time of day, any time of night... "Look outside, something just happened," or, I don't know, I know that one night, a helicopter came and it flew over the house, but it [the helicopter] was too low, and that the helicopter was against the law. I knew, but we couldn't do anything much about it, and they directed their light into our windows, and Patrick started yelling after them, with the gun in his hand, and saying, "You won't get me! You won't get me, god damned son of a bitch!" He was yelling that it was the FBI who was coming to get him because of the games that we recorded on the computer and the movies that we did record.

She also described his depressive episode that tragically ended in suicide:

He was so depressed that he said, "Oh, I should kill myself. I'm gonna do it." And I started to cry and... "No David, this is not the door out of this. I know you have pain, I know you're suffering, but this is not the way out. There are other things. You can go see another doctor, you can go to a psychiatrist, you can call, see what's available to help and he said, "Nobody can help me." He said, "I just wanted the pain to go away and they can't take my pain away."
Query: How did you respond to that?
I just started to cry and then I stopped talking to him and then I went to my room, closed my door and just cried.
Query: Did your father-in-law ever try to physically harm his body, himself or...?
He killed himself. After Christmas he asked Sean if he had a beautiful Christmas and he said, "I love you, son," and everything, and Sean had said that it was a beautiful Christmas he had, and I think it was the 3rd of January. He got one of his guns out and he'd hold it a bit. He put his gun behind his sofa, his chair in the living room, because in the morning he wanted to shoot squirrels...squirrels. But normally he'd never do that. Normally he'd just take the gun in the morning and shoot them. That's when I realized that he was going to commit suicide. He stayed in the bed with my mother-in-law all night, which he never did all the time I knew him. That was too obvious, he was going to kill himself. So Saturday morning, the 4th of January, my mother-in-law went to the hair salon and during, I think it was about 9:30, I heard the gunshot. I woke up, sat down in my bed... I didn't want to realize that it was him. We lived in the woods, so I just put in my mind, it was the neighbor who shot a cat or something like that. I didn't want to realize that. I just got back to sleep and I'm a light sleeper, like I told you, because when he shot himself, I heard his last breath, that it was a breath, and that's the last one I heard after that. Around 10:30, Lucille came back from the hair salon, and I heard the door open, and I didn't want to wake up. And after I heard her yelling, as if yelling... ripping, inside, like then I knew that it was true, what I heard, and I had been shaking a lot, and Sean asked me what was happening, he heard his mom crying and he ran to the living room and he saw his mom and father, and he just ran towards the body and just jumped on the body, saying and yelling, "I love you, daddy, I love you, daddy," and I was standing in the entrance of the living room, in the middle, I couldn't go backwards, I couldn't go forwards and my legs couldn't go. My feet

> were frozen to the ground, and I just watched my father-in-law, with a hole in his head, and my husband yelling after his father. It took half an hour to do something else, you know, he was just yelling and crying and after half an hour she started to running around in circles in the kitchen and she kept looking at the body and I was almost peeing in my pajamas. I looked at Sean and I told Sean that we should call the police.

Five of the women in the study reported the dangerous use of fire by family members during manic and depressive episodes that were clearly a danger to themselves and others. Women reported the dangerous use of fire such as: 1) a family member had set themselves on fire 2) a family member repeatedly set fires in the backyard 3) a family member set a fire in the dining room and 4) a family member lit candles and placed them dangerously close to bedroom curtains. "Ruth", a 48 year-old sales clerk and caregiver of a 52 year-old chronic manic depressive sister recalled that her mother had set herself on fire during a depressive episode "*When she was really depressed. She set her quilted housecoat on fire while she was wearing it.*"

Tracey described how her mother repeatedly set fires in the backyard during a manic episode:

> My mother may never have ever been in trouble with the police, but she does break the bylaws repeatedly. We're not allowed to start fires in our backyard. She has a pit that she starts fires in, and it's not allowed because the grass could all blow up and there's a lot of farms out there, and it could ruin the crops.

Monica recalled how her sister set a fire in the dining room during a manic episode:

> ...she'd burn things, she'd engrave things on walls, in orbs in glasses, and spray things in the house... I just remember her saying there was an instance Easter time when around 1995, I had not come up, but she had taken the arm of a chair, a muffin, a

> Kleenex, threw it in a bowl and she took it and she lit it on fire. It was in my parent's house, she put it in sort of a bin area out front. She lit 20 candles, some on the wooden wall unit over the dining room and she had a tiki torch, she lit that, and she made a fire and she watched it die down...she said [mother] she could have started a house fire, because the candles that were on the wall unit, it was wooden wall unit. Mom put all the candles out, the way Kyla described it, it was like Jesus Christ has risen, he has risen, it was to purge us of all our sins. She was getting all these religious ideas and she was mixing them up, it was all very confusing, we didn't understand where all this was coming from, my dad had a very bad reaction to that.

Eleanor recalled how her son lit candles and placed them dangerously close to bedroom curtains during a manic episode:

> ...I used to have terrible worries about candles. Jake was obsessed with candles, and had to have lit candles all over the place, and sometimes they were really close to his curtains and I would just think, if he catches his room on fire...

These women have to contend with the frequent manic and depressive episodes of their family members and the unpredictability of harm to themselves and/or others that often accompanies these episodes. Little wonder that many of the chronically mentally ill are caught up in the criminal justice system (Porporino and Motiuk 1994) which causes additional tension amongst these women and their family members.

4.3 Exercising Skill and Its Limits

While these women are socially, politically and economically disadvantaged by the macro caregiving context, they are not helpless. These women reported exercising a complex form of power in the governance of their chronically mentally ill family members in order to manage problems, issues, tensions and contradictions that are present at both the micro and macro that includes: 1) monitoring and controlling manic and depressive episodes, 2) monitoring and controlling medical compliance, 3) monitoring and controlling outpatient hospital treatment, 4) monitoring and controlling hospitalization, and 5) monitoring and controlling medical file information.

However, these women reported that this complex form of power has its limitations in that it is constantly being negotiated and altered within constraints and resistance by their family members. These women also reported that this complex form of power has its limits in mental health legislation and policy and the contradictory liberal rights and medical model discourses that devalues caregiver knowledge and reinforces the rights of chronically mentally ill family members both to receive and to refuse treatment. They reinforce and reject the medical model of madness and present a paradox that grants contradictory liberal rights to chronically mentally ill family members of involuntary admission and detention criteria; informed consent; capacity to consent; substitute consent; compulsory treatment; confidentiality and disclosure of clinical records; and review conditions to the chronically mentally ill.

Monitoring and Controlling Manic and Depressive Episodes

All women in the study reported the governance of their family members in monitoring and controlling their manic and depressive episodes, with resistance such as: 1) governance during a hypo-manic episode prior to work only to be met with resistance in that the family member decided to go to his office in this episode 2) governance during a manic episode of fraudulent charges and excessive spending only to be met with resistance in that the family member refused to rectify the charges and excessive debts and 3) governance during a manic episode of delusional accusations of theft only to be met with resistance in that the family member refused to address her false accusations.

Maureen described how the governance of her manic depressive husband was met by his resistance when he decided to go to his office and work in a hypo-manic episode despite her insistence not to do so:

> ...he [husband with chronic manic depression] in a hypo-manic period prior to getting too high, he's extremely productive, he loves to work, he wakes up early in the morning and, or will stay up late at night working in the office. If he has outside work at this point, its very wearing because he does not recognize if people can see that he's getting high, or if he's speeding up too much.
> ***Query: What do you say or do during the manic episodes?***
> Well, once he realizes he's manic it's better because he wants to do something about it, before it gets worse.
> ***Query: Does he realize this on his own?***
> No, I'd have to tell him, and I'd have to tell him quite a few times.
> ***Query: Okay, then how does he respond when you tell him?***
> Irritated, it's not so much to say that he is hypo-manic it's me saying, "Andrew, I really don't want you to go into that office at 7:30 in the morning, and if there is any of this work you can do at home, do it at home instead, don't go into the office," and for him, he feels so good.
> ***Query: And how does he respond after that?***
> Yes, he feels like he can get away with it.
> ***Query: Have you experienced confrontation, or conflict around how to deal with his manic episodes at any point?***
> Oh yes, definitely yes.
> ***Query: Can you tell me a bit about the conflicts that you've had?***
> Well, they're like arguments, me raising my voice, getting very angry, telling him what I'm going to do, what he can do, what he can't do.

Ingrid described how the governance of her schizoaffective daughter was met by her resistance in her refusal to rectify fraudulent charges and pay excessive debts incurred during a manic episode:

> ***Query: What other conflicts about her behavior or the way that she looked or any of her feelings in the mania that you've experienced with her? You mentioned earlier about the way she dressed?***
> Her dress wasn't acceptable. Comments she's made. The comments she's made. I would react to them, I got very angry and took the phone from her, when she turned out to be calling Germany or something.
> ***Query: Were there other things that she had done during the mania?***
> Spending money of course. She gave $500.00 just to somebody on the street and things like that.
> ***Query: Why? When she did things like that ... giving the $500.00 that was a problem during the mania? What happened when she did that? Whose money was it? Can you tell me what happened?***
> That was the money from the bank. She'd taken $5000.00.
> ***Query: What had happened briefly about this time with the $5000.00? Was it in a manic episode?***
> It must have been manic. Yes.
> ***Query: Can you tell me briefly about what happened with the bank?***
> Well she did this and she wasn't living here, so I wasn't aware of it right away.
> ***Query: What did she do? Can you tell me a bit about what happened? How did she get the money?***
> Well she put an envelope in the bank saying that she was depositing $5000.00 or $2500.00 I'm not sure. She put the deposit in and then the next day she came to do a withdrawal on that money. She actually had $600.00 in the bank and the rest was $4000.00 that she had taken out and apparently one of the things was, she walked out of the bank and gave $500.00 to somebody at the Birckdale Shopping Plaza or something like that.
> ***Query: So she gave freely of her money?***
> Yes, and she bought a purse for $150.00, then she bought boots for $200.00 and then the money was gone. She bought me something. It happened that I got a present and I didn't know and she would go out to a restaurant or something.
> ***Query: How did you respond when you heard about it or what did you say to her when you heard about it?***
> Well I was very upset and angry with her. She was probably in the hospital at the time. I'd gone to the bank and said that I would be responsible for her returning the money, not that I would hand them $5000.00. So there was an agreement made out. I was involved in it. She signed a paper.
> ***Query: How did she respond to you getting involved in that, with the agreement that you made [with the bank]?***

> ...she got very co-operative when she wasn't manic. She realized that something was wrong. She was very co-operative about it. She wasn't angry at me for making the arrangement that she had agreed to. But it was only because she was manic that it happened and there was a question of her signing over. She got $900.00 [federal government assistance for persons with disabilities] a month at that time. She signed $600.00 [out of her assistance cheque] to pay back the debt and she kept $300.00. They [the bank] were very considerate of her.
> ***Query: How did she respond to you being part of that agreement?***
> Originally when I found out she was still manic. I said I'm going to go to the bank and she said, "No, it's none of your business." That was her initial response at that time.
> ***Query: How did you respond when she said that it's none of your business?***
> Well, I said "It is my business because you've created another felony and the police could be brought in. You could go to jail. It's that sort of an offense. You've got to make some sort of amends. You've got to try and pay it back."

Tracey described how the governance of her schizoaffective mother was met by her resistance in her refusal to address her delusional accusations of theft during a manic episode:

> I confront her [mother with chronic manic depression with schizophrenic tendencies] every time that she's manic because she always picks a fight with me, so I have to confront her and I have to defend myself.
> ***Query: Can you briefly give me an example of what happens during a manic episode?***
> Well, she was getting paranoid that I was stealing her things, like with the napkins.
> ***Query: What happened? Were you at her place?***
> I was at her place for a couple of days. She accused me of taking all her napkins and hiding them on her so she would think she was crazy. She forgot to check the laundry basket because that's where they all ended up after dinner the previous few days and she completely forgot about it and she thought I was lying when I said I couldn't find a napkin and she said, "You hid them on me."
> ***Query: And how did you respond?***
> After about five or ten minutes of her running around the house like a fool, I said, "Check the laundry basket." And she did, and she said, "You're right, they're all here." And every time after something's gone missing, I say, "Remember the napkins?" Her

> response is, "I don't want to talk about napkins. We're talking about this now."

Some women reported that at times they would not attempt the governance of chronic manic depressive and schizoaffective family members for fear of resistance from chronically mentally ill family members and for fear of exacerbating these episodes with potential harm to themselves and/or others. This interview with Gail clearly illustrates the chronic episodes of her two family members and her fear of resistance:

> Things are dark and things are gloomy [for her mother]. I think she [mother] often expresses that she wants to tear her clothes off and that sort of thing. It's a very dark and gloomy type of thing for her.
> ***Query: What about the behavior and appearance of her during the depressive episodes?***
> She' s quite angry. There' s a lot of anger. Her tone of voice is a lot harsher.
> ***Query: What about appearances?***
> I guess she doesn't look too good.
> ***Query: And what do you say or do in response to her behavior and appearances during her depressive episodes?***
> Well nothing much. I don't feel that I have the freedom to voice my thoughts, my openness, my feelings.
> ***Query: What kinds of feelings does your brother experience during these episodes [depressive]?***
> He's much quieter. He's more withdrawn; he's that sort of way. He doesn't talk much.
> ***Query: And what kinds of feelings does your brother experience during his manic episode?***
> I don't know because he's never really told me what he feels or how he feels.
> ***Query: What kinds of behaviors does he exhibit during his manic episodes?***
> Like I say. He's quite withdrawn and he's very quiet. He'll probably go off in his room and listen to the radio or go out at one o'clock in the morning for a walk.
> ***Query: With his manic episodes? In mania?***
> Yeah. He'll go out for two hours at one o'clock in the morning. He wouldn't know where he's going or else hopefully he won't have another attack that he's going to do something foolish.
> ***Query: What do you say or do about his behaviors in his manic***

> ***episodes?***
> I don't really do anything, you learn about what to say, what to do and how to do it because I'm afraid it's going to trigger something more serious or whatever.
> ***Query: Do you feel like that about both of them [mother with chronic manic depression and brother with chronic manic depression and schizophrenic tendencies]?***
> Yes.

While women in the study reported the governance of their family members in monitoring and controlling their manic and depressive episodes it is likely to be met with resistance that most often has difficult and sometimes tragic consequences for both caregivers and family members involved such as criminal charges, harm to themselves and/or others. These women also monitor and control medical compliance in the governance of their family members to try to monitor and control the manic and depressive episodes of their family members and prevent these criminal charges, harm to themselves and/or others.

Monitoring and Controlling Medical Compliance

All women in the study reported the insistence upon medical compliance in the governance of their family members, with nine of the 17 chronically mentally ill family members refused to comply with medical treatment for their manic depression and schizoaffective disorder. This resistance is facilitated by current mental health legislation, in that consent is necessary before a chronic manic depressive and schizoaffective family member can receive treatment in Quebec (Gaudet 1994:22). In Quebec, treatment can be given without consent to chronically mentally ill family members only in an emergency situation, where a psychiatrist believes, "on reasonable and probable grounds", that the patient is in imminent danger. Similarly, in Ontario, treatment can be given by a psychiatrist without consent from a chronic manic depressive and schizoaffective family member only if the person is suffering and is at risk if the treatment is not administered promptly. Thus, in Quebec and Ontario, efforts by these women to administer treatment to family members and insist on medical compliance without their consent may be met with resistance and prove to be both significantly challenging and frustrating for these women left to rely solely on the judgement of a psychiatrist in determining "need" in order to administer involuntary treatment, as required by the provincial mental health legislation of Quebec and Ontario. The legitimate authority to diagnose chronic manic depression and schizoaffective disorder and prescribe medications rests with psychiatrists and medical practitioners while these women are given the responsibility of overseeing medical compliance and managing symptoms and behaviours of their chronically mentally ill family members.

These women reported that medical compliance for their chronically mentally ill family members was important to: prevent harm to themselves, prevent manic and depressive episodes, help them function and control manic depression as a biochemical disorder. Monica insisted that medical compliance was important and reported "*I think it's really important to keep them [manic depressives and schizoaffectives] from damaging themselves, and to prevent episodes from coming around.*" Again, Nicole insisted that medical compliance was important and stated that "*it stops the severe highs and lows. It keeps them on a level where they are not so high and low. It helps them function throughout daily life.*" Similarly, Amanda argued that medical compliance was important and maintained "*it's [manic depression and schizoaffective disorder] chemical, right? So yeah, if it can help.* "

The majority of women in the study reported the governance of their family members in using explanations of mental illness embedded within the medical model of madness to emphasize the significance of medical compliance and persuade them to take their medication, with resistance such as: 1) comparing manic depression to diabetes and having to 'fix the imbalance" to convince a family member to take medication only to be met with resistance in that the family member refused to take the medication 2) insisting that one had to "adjust to the right medical levels of medication" to convince a family member to take medication only to be met with resistance in that the family member refused to take the medication and 3) comparing manic depression to diabetes and epilepsy to convince a family member to take medication only to be met with resistance in that the family member refused to take the medication.

Nicole described how the governance of her schizoaffective husband was met by resistance in his objection to medication:

> I tried speaking to him. I told him, "You have an imbalance in your head" and I touched his head to show him. I said, "You need the medication to control this." I also said... touching my own stomach that my pancreas does not work and if I don't take medication, I will get a bad case of diabetes. That is, I don't have enough insulin to take care of the sugar that goes into the blood. Therefore, I take insulin needles, and regulate it by medication. I told him that he does not have enough serotonin in his brain, so the doctors made pills to fix the imbalance in your head. He said if he takes the medication he will become addicted to it. He said he does not want that. I said he has to take it because his illness is physical and he needs the medication. He said he did not want to take pills and have people know he had a mental illness. He was too proud.

Eleanor recalled how the governance of her manic depressive son was met by resistance in his refusal to take his medication:

> ...[I] tried to explain to him that it was like a person with diabetes they had to, or by right, you had to test, you had to do bloodwork and observe how the person was feeling and adjust to the right medical levels of medication but it took time. But it didn't work and besides he didn't want to take the stuff it was scary stuff. He objected and now, I don't know whether he is on anything or not.

Monica explained how the governance of her schizoaffective sister was met by resistance in her objection to medication:

> ...most of the time I would say, "You're not going to get better if you don't start taking it regularly and properly." I tell her it's like a diabetic taking insulin, that works, or an epileptic taking medication to prevent a seizure. You need to take that medication. I have to keep explaining to her a lot of times she blames herself for her mental illness. But I say, "You have a chemical imbalance, it's just like someone with a pancreas that doesn't produce insulin. You need to take that to stabilize yourself and you need to be on it for a period of time. Because if you are not on it and you don't eat properly and you don't take it the right times you'll start to mess everything up. Your brain will start to get messed up again." I just try to emphasize how important it would be to take it properly because if she doesn't take it she is not going to get better.

The majority of women in the study reported the governance of their manic and depressive family members in their insistence that their family members take their medication, with resistance such as: 1) surveillance for the purposes of medical compliance only to be met with resistance in that the family member refused to take medication 2) providing containers for medication only to be met with resistance in that the family member would not take the medication and throw it away and 3) putting medication in cereal and milk only to be met with resistance in that the family member would not drink the milk in suspicion.

Nicole described the governance of a family member through medical compliance by surveillance that was met with resistance in that the family member refused to take medication:

> I watched him night and day, and it was hard to get him to take the medication. Once, I had to call his sister who spent a whole night explaining to him how important it was to take it. Well, when he stopped, he was in a high and you cannot reason with him.

Ingrid reported the governance of a family member by providing containers for medication that was met with resistance in that the family member refused to take the medication "*forgetting them or throwing them away a few times.*" She said " *I'd give her the containers. Take three a day and she'd forget. She wasn't interested in taking it, she wasn't responsible.*"

Gail described the governance of a family member by deception by putting medication in cereal and milk that was met with resistance in that the family member refused to take the medication :

> ...he is now taking medication without him knowing it, and I believe the lithium is helping.
> ***Query: How is it that he doesn't know?***
> Because he doesn't think that he has an illness or he doesn't think that he needs any medication.
> ***Query: But is he taking it by his choice?***
> No he's taking it without knowing it. We [Gail and her mother] administer it. Half a tablet in the morning in his cereal.
> ***Query: Ok.***
> That's the lithium, but at night he takes another medication, which he doesn't take all the time, because that's harder to give to him, because sometimes he takes orange juice rather than milk, and we put it in the milk. Like last night mother put it in his milk, but he didn't take the milk, he took the orange juice. It's easier to hide it in the milk than it is in the orange juice.

> ***Query: If he's got suspicious does he ever say anything?***
> Well, we say, "Here, we've poured you your milk."
> ***Query: Has he ever got suspicious and asked you anything about it?***
> Yeah. He has.
> ***Query: How do you usually respond when he does that...or your mother? Who responds?***
> Just a brief point for you. We ask,"Do you want to empty the carton?"
> ***Query: Does he persist or does he drink it?***
> Sometimes he won't drink it. Sometimes he'll go and get some more from the carton. In that case it's just left and it will get thrown out.
> ***Query: What ideally would you like to do about your brother? What would you say was the ideal situation about dealing with how he's not taking the medication? Your technique now of administering his medication is that the ideal solution that you've found?***
> What else is there? You run out of ways how to do it.

These women reported that the governance of family members through medical compliance is met with resistance because of side effects and other demands of long-term treatment and various types and dosages of medication that may be burdensome such as feeling ill, ceasing to menstruate, weight gain and feeling constricted. Monica explained that for her sister with schizoaffective disorder, medical compliance was often met with resistance because she felt ill on various dosages and kinds of medication:

> ...there will be times where you know she'd go off and say, "I don't want to take them...I don't like the way they make me feel." There were times where she'd be on the wrong dosage or she's not on the right kind. There were a lot of times when she was in the hospital, the last time she was in treatment, they put her on different medications trying to find the right combinations and she was getting pretty bad side effects. So I kind of could understand why she wasn't taking it properly because it's not until recently that she was put on the right combination. Before in the hospital she was put on too strong of a dose or other types of drugs.

Diane noted that for her daughter with schizoaffective disorder, medical compliance was often met with resistance because she ceased to menstruate and gained weight:

> Her meds stops her having periods, and she doesn't like that, she also thinks it makes her put on a little weight, I think eating has something to do with it, makes her put on a little weight, I would say she is ambivalent.
> ***Query: What do you say or do about it?***
> I say, "Well, I see that your injections are coming, I see that you are a little crosser than you used to be." I say, "The choice is yours you may turn up and get your meds and you are entirely welcome here, but if you choose, if you do not take your meds, then it is very clear, I choose not to have you here."

Ingrid stated that for her daughter with schizoaffective disorder, medical compliance was often met with resistance because she felt constricted:

> I know that the Haldol... this is not what she's taking now...this thing will tranquilize an elephant. I feel that she must have felt so constricted under Haldol. I thought that because naturally she wanted to break out and she said, "I can't stand it, restricting, restricting" and then she'd go and take cocaine or something.

These women also reported that the governance of family members through medical compliance is met with resistance because of reluctance to give up the experience of manic episodes of euphoria, increased energy, creativity, heightened self-esteem and ability to focus that accompanies these episodes. Eleanor stated that for her son with chronic manic depression, medical compliance was often met with resistance because he was afraid of losing his creative abilities:

> ...Jake was afraid that if he took his lithium that all his creative abilities would disappear....he was afraid of that because he's always been very visual, very creative, always liked drawing. I guess he has designed for years and years and we didn't know about it, and very musical, incredibly musical, and I think he was afraid it would dull his brain or something, and I know that was the thing he was afraid of.

> ***Query: So what did you do about it, when he wouldn't take his medication?***
> There wasn't a hell of a lot I could do, I just encouraged him to do it and he said no.

Despite this governance, over half of the women were unable to persuade their family members to take their medication. Many factors including denial, ambivalence and side effects contributed to family members resistance to medical compliance. The safeguarded rights of chronically mentally ill family members in mental health legislation also facilitated their resistance. These women also monitor and control hospital outpatient treatment in the governance of their family members to try to monitor and control the manic and depressive episodes of their family members and secure professional treatment for their episodes.

Monitoring and Controlling Hospital Outpatient Treatment

The majority of women in the study reported the governance of their manic and depressive family members in using psychiatrists or medical practitioners for outpatient hospital treatment, with resistance such as: 1) governance in using a psychiatrist and this was met with resistance in that the family member refused to go to the appointment 2) governance in using a psychiatrist and this was met with resistance in that the family member became very hostile and refused to go to the appointment and 3) governance in using a psychiatrist and this was met with resistance in that the family member became very defensive and refused to go to the appointment.

Sheila described the governance of a family member by using a psychiatrist that was met with resistance in that the family member refused to go to the appointment she *"tried, I tried getting him into see a psychiatrist and there was no way of getting him there, there was no way. Well, I called the next day to set up an appointment and she [the psychiatrist] said yes she could see me the very next day and he just didn't want to go."*

Diane described the governance of a family member by using a psychiatrist that was met with resistance in that the family member became very hostile and refused to go to the appointment:

> We couldn't get her near a doctor for the first I would say two to three months when she could no longer function at school. She felt everybody was looking at her, she was very uncomfortable, she stayed home, and she quit school, in other words Cegep. Then I became very ill with pneumonia very soon after. At the hospital I met a very wonderful lady physician at the time, a general practitioner an excellent doctor, and I told her why, what I was dealing with.
> ***Query: Do you remember what year that was in?***
> Oh yes, it was I would say in about '88 would it be, it was four years from her diagnosis, four years from whatever I said before anyway. I told her about this problem with my daughter, the abusive behavior...
> ***Query: Did your daughter willingly go in?***
> I think reasonably willingly. I didn't have a problem or anything, I didn't drag her.
> ***Query: Was there any kind of resistance?***
> I think there was resistance towards pretty well everything, I don't recall a smile on her face for three or four years.
> ***Query: What did she say or do, when she thought you might have recommended her?***
> Probably fuck-you or something, but after that, I may have set down a few guidelines, and pardon me for that language, but I was being her, she. I think we were getting to the point of if you're going to live here and we want to keep our health, you're going to have to get in a car with us and see a doctor. I just got over pneumonia, and I don't plan to be sick again if I can avoid it, for my health, and we went over and the doctor saw something pretty serious, her hair was out in a funny way and of course the scowl on her face. She had a permanent scowl for about four years, then she set her up

> with a doctor, a psychiatrist at St. Antoine's Hospital. We got there, and she did go for a year at our insistence, sometimes, she pretty well went most of the time, again, reluctantly I guess she didn't want to be out in the street. I didn't want to put her out in the street, but tough love is cruelty with a really sick person but anyway we got her to the doctor finally he said "family meeting", I thought this was much better.
>
> ***Query: So he called the family meeting, so how did your daughter react to that?***
>
> She wasn't going to go and I said "If you do not go get in the car with us we are going, we have planned and waited for this day for quite some time and I said if you do not get in the car with us, you must make other accommodations, you will be removed, you will not live here." So she got in the car and we left, and we got there and she did listen to him, and she was very angry, but she was genuinely frightened at being…all of her friends had gone, they're gone through university and they got degrees, she was stuck in a basement for four years, enough is enough. So she did go.

Nicole described the governance of a family member by using a psychiatrist that was met with resistance in that the family member became very defensive and refused to go to the appointment:

> …he would say that he was not sick. In July of 1994, my girlfriend Marie set up an appointment with a psychologist and psychiatrist for him because in July of 1994, he slept on the sofa for 24 days. Once a week, I bathed him, I brought all his meals into the living room. We tried to get him to go to the psychiatrist and psychologist. But he would not go. Marie tried to get him to go because he would not listen to me at all. Marie could not convince him either. In fact when Marie and Paul had a one on one conversation, he switched the whole conversation of going to the psychiatrist and psychologist to all his problems were my fault. I, in his eyes, needed help and not him. I told him, he was using me as an excuse to cover his problems. I told him that if I was the real cause of his problems, I would stop doing everything that he did not want me to do. He just ignored me and tuned me out.

While women in the study reported the governance of family members in using psychiatrists or medical practitioners for outpatient hospital treatment, many women were unable to persuade family members to attend appointments with psychiatrists or medical practitioners without resistance. Denial was the primary factor that contributed to family member resistance to appointments with psychiatrists or medical practitioners. These women also monitor and control hospitalization in the governance of their family members to try to monitor and control the manic and depressive episodes of their family members and secure long term in-patient treatment for their episodes.

Monitoring and Controlling Hospitalization

The majority of women in the study reported that the governance of their manic and depressive family members was met with resistance. Resistance to hospitalization is facilitated by current mental health legislation. Under Quebec legislation, a chronically mentally ill family member cannot be admitted involuntarily, without a psychiatric examination; however, if a physician finds that the person poses a serious threat to himself or others, that person can, under section 21, can be held for 24 hours in order to undergo a psychiatric examination (Gaudet 1994 20). Involuntary admission of a chronically mentally ill family member in Quebec requires two psychiatric assessments (with the same conclusion) within 96 hours. In Ontario, however, one physician may give authority for involuntary admission of a chronically mentally ill family member based on the potential danger posed by the person.

These women reported resistance to using hospitalization in the governance of chronically mentally ill family members such as: 1) governance in using a hospital for emergency hospitalization and this was met with resistance in that the family member used the Mental Health Act to avoid hospitalization 2) governance in using hospitalization only to be met with resistance in that the family member got out to write an exam and didn't report back to the hospital and 3) governance in using a hospitalization for emergency hospitalization and this was met with resistance in that the family member ran from the hospital grounds. Monica described the governance of a family member by using a hospital for emergency hospitalization that was met with resistance in that the family member used the Mental Health Act not to be admitted:

> We were given a really hard time when we came in. I don't think anyone took us seriously.
> ***Query: Were you ever denied any information or did your sister ever deny any information about treatment or anything?***
> I don't recall them [the social worker] going over the workings of the mental heath act [at the hospital].
> ***Query: When was the Mental Health Act raised with the social worker?***
> I think it was when I asked...when I wanted to admit her.
> ***Query: What year was that?***
> 1995.
> ***Query: So what happened that time you wanted to admit her?***
> I brought her in. We walked into emergency and the lady at the desk... they didn't take us seriously... I think they thought we were a lot younger then we were. A long wait and finally we got to see the social worker. We talked to her a little bit. Kyla talked to her, not much else happened after that... I remember talking with her and she said I think that we should keep her. It would be advisable for her to stay here for a few days. She said but we can't keep her against her own will here. They probably told me about the Mental Health Act. They didn't really go into detail. I never got any kind of sheet on the Mental Health Act, just sort of like it has to be her choice to stay here.
> ***Query: Did she want to stay there?***
> No, no. She didn't think she was sick. She didn't think anything was wrong with her.
> ***Query: How did the situation end?***
> We ended up going home. I think when they were talking with me for a little while and they talked to her and they brought us together afterwards and talked with both of us... I think they made it look less serious, when we were together then when we were giving our

> own separate explanations.
> *Query: How did your sister respond at that point to the contact that you had had with these professionals?*
> Pretty badly.
> *Query: What did she say? Do you remember?*
> She was very on the defense. I don't believe that at that point she thought there was something wrong. She'd say I'm fine. They'd ask her questions like name, marital status. She'd give her name, date, whatever and she'd go, "What do you think I am sick or something?" I'd go Kyla, I'd go into some of her behaviors, "I don't think that's exactly average behavior, I mean I think you've got some problems that you have to sort out." Maybe I wasn't always sensitive and go, "Kyla I think you might be sick." The social worker whomever we talked to said yeah, "We think that she should stay here for a while for observation." She was not compliant at all.
> *Query: What ideally would you like to do about that contact with professionals?*
> I think I would have liked for her to spend enough time with us. I think they did not spend enough time with us. I think they were trying to rush everything to get us out. I think they should have gone over a little more with the Mental Health Act. I don't really think they took us seriously... what was going on... I think she [the social workers] was kind of making light of it. I think I would have liked for it to be taken a little more seriously. I don't think they took us very seriously at all.
> *Query: What did they explain to you about the mental heath act, if you can recall?*
> I don't even remember the words Mental Health Act. I just remember them saying she has to be the one that wants to stay here, you can't force her against her will that's the law. That's all I remember I don't remember her going over the mental heath act, like the director mentioned in that letter. No one read us the riot act. I never saw any sheet, Mental Health Act, and how it runs. I found out from research and talking to other people later on.

Ingrid described the governance of a family member by using hospitalization that was met with resistance in that the family member got out to write an exam and didn't report back to the hospital:

> *Query: In terms of the hospitalizations, how many of them have been voluntary out of the thirty-seven? Were there any at all?*

> Well none of them were really voluntary. There were times before certification where she would run away and I'd have to bring her back [to the hospital grounds].
>
> ***Query: Is there any resistance in doctors or others?***
>
> Well, doctors have to have the word, Dr. Kovic said to me. But certification means that if they leave the hospital, it's the hospital's responsibility to find them. They have to phone the police. They're responsible for bringing her back if she is certified, but if she's not certified she's just committed. *Committed* that's the word I was thinking of, but they're not certified. If she's committed and she leaves the hospital, I have to find her. They don't usually certify them for longer than twenty-four or thirty-six hours, but they can repeat it.
>
> ***Query: Were there ever any times that you brought her into the hospital and attempted to get certification for Arianne and not obtained it?***
>
> Well, you don't usually get certification the moment you take them in. Maybe a few times when she was crazy, crazy, crazy.
>
> ***Query: And were there times when you felt that she should, and they felt that she should not be certified?***
>
> Well, there was a mistake made one day. One day they took her in and she was writing exams at Bridgeton University and I got a form from the doctor that could take her in the exam and then go back to the hospital and that happened a couple of times; and then the third time the doctor was very apologetic. That was the only way she could get out, so she probably was certified. She got to write the exam and then somebody missed something and she got out with a girlfriend and she got manic again.

Monica also reported the governance of her family member by using a hospital for emergency hospitalization was met with resistance in that the family member ran from the hospital grounds:

> ...there have been times where we have gotten onto the premise and she sort of runs off.
>
> ***Query: How does she respond to this?***
>
> I think a lot of the times she gets verbally aggressive. Sometimes physically but I don't think she's terribly thrilled about it [to go to a hospital emergency room].

Further resistance to hospitalization is facilitated by cuts to mental health care services and problems in providing community-based services to the chronically mentally ill that tend to be underfunded, uncoordinated and unequipped to deal with the severity and chronicity of certain mental illnesses (Gaudet 1994).

The women in this study reported long waiting periods due to understaffing as a result of mental health care cuts that facilitated resistance. Ingrid and Nicole reported the following: 1) resistance to hospitalization in the family member fleeing from the hospital waiting room and 2) resistance to hospitalization in leaving from the hospital room and attempting suicide. Ingrid described the long waits due to lack of staff as a result of mental health care cuts that facilitated her daughter's resistance to hospitalization in fleeing from the hospital grounds after her twentieth visit to emergency:

> ... what I thought after she was going to the Glenview Hospital and all the files they had. It shouldn't have been such long waits. That was interminable. Just waiting in the emergency. They can just run away and do all sorts of things. It's long waiting periods. You know, if they had a patient that they knew was there every seven months, at the twentieth time they came, they should have been able to look up a file, you know, not have these ages of waiting.

Similarly, Nicole described how her husband was left unattended due to lack of hospital staff as a result of mental health care cuts that facilitated her husband's resistance to hospitalization in fleeing from the hospital grounds:

> ...she admitted him and they were supposed to come and give him his pills to sedate him and a psychiatrist was supposed to come and speak to him and nothing happened. He was left in the room for a few hours by himself. When he was left alone, at that time he was in psychotic paranoid state, but none of the doctors or nurses knew this or picked up on this. So he would wander around the room and say to the nurse that he wanted to go for a walk around the parking lot. The nurse allowed him but said he could not leave the hospital premises and that he had to be back in a couple of minutes. He did and masked it. He put on a smile and very friendly and acted normal.

As Nicole further explained, this resulted in his near fatal suicide attempt:

> He left the hospital and walked to the mountains behind the bushes in the freezing rain and snow. He got lost, took his belt off and hung it on a tree to hang himself. But it didn't work because the buckle broke off. He fell and I guess he slept for a while because he was unconscious. He woke up and I guess that he realized, he wanted to live for me. And, then he walked to his brother's house and got there at 2:00 am. He had a big, thick red mark around the front of his neck from the belt.

While women in the study reported the governance of their family members in using hospitalization with family members many women were unable to hospitalize family members that were a danger to themselves and/or others without resistance. Denial and ambivalence contributed to family members' resistance to hospitalization. The safeguarded rights of chronically mentally ill family members in mental health legislation and long waiting periods in emergency rooms as a result of mental health care cuts also facilitated their resistance. These women also monitor and control medical file information in the governance of their family members to try to monitor and control the manic and depressive episodes of their family members and their medical compliance.

Monitoring and Controlling Medical File Information

The majority of women in the study reported the governance of their manic and depressive family members in attempts to obtain medical file information of family members, with resistance. Resistance to obtaining medical file information is facilitated by mental health legislation. Ontario and Quebec include confidentiality provisions in their mental health legislation, despite the fact that confidentiality is required under professional codes of medical ethics. Information about chronically mentally ill family members is gathered and provided to facilitate effective treatment for the patient, in some cases after the patient has been discharged to a community facility. Hospital staff have a strict duty to keep all information from psychiatric records confidential, in consideration for chronically mentally ill family members and the potential consequences of the improper release of information.

These women reported the governance of chronically mentally ill family members in attempts to obtain medical file information of family members, with resistance such as: 1) governance in trying to secure medical file information of family members with resistance through the use of the Mental Health Act with guidance counselors, general practitioners, and psychiatrists complying with the legislation and 2) governance in trying to secure medical file information of a family member with resistance through the use of the Mental Health Act with psychiatrists complying with the legislation.

Eleanor reports the governance of a family member by trying to secure medical file information of family members that was met with resistance in that family members used the Mental Health Act and guidance counseling. general practitioners, and psychiatrists complying with the legislation:

> I don't know if he's on any medication and it's very frustrating because once they reach a certain age, you could be going, and I've heard this from other people, you could be going through hell at home, but your hands are tied, because once they reach a certain age, "Sorry we can't tell you anything."
> ***Query: Has this happened before?***
> Yes, oh yes.
> ***Query: With which of your sons?***
> Both of them.
> ***Query: And can you tell me a little bit about that? Have you experienced this with Jake or Cory ever before?***
> Yes, with both of them.

Query: With any professionals that you've been in contact with?
Oh, yeah, lots of pediatricians, general practitioners and whoever they were seeing, psychiatrists or even some guidance counselors at school, "Oh, I'm sorry it's confidential information we can't tell you anything." And you could be going through absolute hell with them if they won't tell you anything.

Query: With Jake with whom and did you ever, with what professionals did you ever experience barriers of confidentiality?
Guidance counselors at school.

Query: What year, do you remember?
Oh at 14, 15. When he was going through high school with a guidance counselor.

Query: What happened at that time?
Well I knew his behavior was weird and I really had no idea what was going on at school and I didn't know what his behavior was like at school and I made an appointment to talk to the guidance counselor and I knew he'd talk to them. They wouldn't tell me anything because it was confidential and I went in and I tried to say well this is what's going on at home and I'm very worried and I know its not normal and they said, "I'm sorry I can't talk about it."

Query: Were there any other professionals where you ran into these problems with Jake, experienced barriers?
The psychiatrists at the hospital, they're not allowed to talk about it, about what the other person said and the general practitioners. My sons asked me to make an appointment with the general practitioner's for Cory, because he was feeling depressed. Yet when I saw Patrick, who's a friend of mine, cause I taught his kids, "I'm sorry I can't say anything." "Did you see Cory, did you see him?" "Yes," and he couldn't say anything cause it's confidential. I mean how the heck do you know? It would be nice to know, well yes the medication is helping, no it's not, we're assessing the levels. It's very important to send them in too. I mean it's like beating your head against a brick wall, they won't say anything and how in heaven's sake can you help yourself and them if you don't know what's going on?

Query: At any point do you feel that Cory or Jake have asked the professionals to secure confidentiality so you would not have access to information? Who's choice do you feel that it was?
Well it's law and I think maybe if I were in their shoes I would feel much better about talking to somebody if I knew it stayed here and maybe this wouldn't get back to my mother, but then it's very frustrating if somebody finds you in that episode and your hands are tied. Nobody will tell you anything, nobody will help you, won't say yes they're on their medication, no they're not on, we're trying

> to address the levels, make sure that they go back. That was the problem with Jake. He wouldn't go back for the blood test to check his lithium levels, so they could adjust it and I tried to explain that like people with diabetes or I have a thyroid problem and you have to find out what the proper level is.

"Maggie", a 23 year-old college student and caregiver of a 44 year-old female chronic manic depressive aunt reported the governance of a family member by trying to secure medical file information with a family member that was met with resistance in that the family member used the Mental Health Act with psychiatrists complying with the legislation "*when she did get to see a psychiatrist, it was very secretive. Even though if a family member requested to be in the room, whatever, that* [sic] *could give information, cause she knew if I was in the room to give information, they could give information to me.*"

While women in the study reported the governance of their manic and depressive family members in attempts to obtain medical file information of family members many women were unable to obtain medical file information on family members without resistance. Privacy was the primary factor that contributed to family members' resistance to releasing medical file information. The safeguarded rights of chronically mentally ill family members in mental health legislation facilitated their resistance.

Clearly, for these women the governance of their family members has its limitations in trying to manage the problems, issues and tensions, and the contradictions they face in their roles as primary family caregivers and as state designated mental health promoters. The governance of family members through monitoring and controlling manic and depressive episodes, monitoring and controlling medical compliance, monitoring and controlling outpatient hospital treatment, monitoring and controlling hospitalization and monitoring and controlling medical file information is constantly being negotiated and altered within constraints and resistance by their family members. Further, this complex form of power has its limits in that family member resistance is facilitated by mental health legislation and policy. Mental health legislation and policy refuses information to these women from psychiatrists or physicians, provides inadequate information about chronically mentally ill family members, provides inadequate mental health services to these women and their family members, excludes these women when they accompany the family member to emergency, ignores these women's knowledge to the detriment of the family member and contradictory legislation and policy repeatedly recognises the right to refuse care as more important than the right to care even in situations where intervention and prevention is required. This places severe limitations and constraints on women in the governance of family members in managing their roles as primary family caregivers and state designated mental health promoters of their chronically mentally ill family members.

Devaluing Caregiver Knowledge

The majority of women reported that when family members were taken to the hospital during manic or depressive episodes, the family members, physicians and psychiatrists denied caregiver knowledge of their episodes, they denied that family members posed a danger to themselves and others and, physicians and psychiatrists misdiagnosed and minimized the severity of their family members symptoms and behaviors. Most often when family members were taken to the hospital emergency room, the family member was not admitted to the hospital and returned home with the caregiver while they remained a danger to themselves and others.

Ingrid reported that a psychiatrist denied her accounts of the severity of her family member's manic episode:

> I know for example when she was at the Glenview and she was an out patient and a very young psychiatrist, from Germany, a physician who was deciding to become a psychiatrist, and Arianne was one of his patients, he used to be a trainee and I knew during that period she was becoming a bit manic and I went and told him that, and he said no, no she's just fine and so the third time I went and said she's really manic and he agreed to call in the senior out patient psychiatrist, and so we were sitting there quiet enough and the senior psychiatrist came. I've forgotten his name and she told him that there was something bad that was going on and this older man was getting upset, "I can insist that you stay in the hospital" and she said, "No you can't" and she ran away. That was...I mean I knew that Arianne was getting manic and this psychiatrist didn't know it until he called in the senior fellow...

Monica tragically recalled how a psychiatrist denied her accounts of the severity of her family member's depressive episode. denied that she posed a danger to herself and others and misdiagnosed and minimized the severity of her symptoms and behaviors:

> ...they had her in the first three times, the first time it was a "nervous breakdown." The second time "a quick kind of you know"...and the third "here's some Prozac, call me in the morning kind of thing of treatment" and we went home again..., and the fourth time it was okay, she has got an established kind of record here [at the hospital]. We've been here this many times, it had to come to a point, where she's trying to kill herself and they literally have to be in the act of doing something, in order for them to get hospitalized, they have to be. I knew that night [the third time] she was going to overdose, but I had to let her do it, because if I didn't let her do it, then I wouldn't have a reason for bringing her in. Like they wouldn't think it was severe enough, according to what they put in the records, they didn't feel that any of that was a threat to herself, a threat to me or to anybody else, they didn't feel that she was a big enough threat to herself or anyone else. I knew by him

> [the psychiatrist] giving her the Prozac, whatever drugs they gave her she was going to take them all. I was going to take them from her and monitor them and I thought no, I know she is going to take them all so I am going to let her take them all and it's all sick but I had to do it...because I didn't force her to take them all but I knew that she was going to do it. But if I didn't let her, the way the mental health system works is the person literally has to be doing something that is like in danger of themselves at that time, at the immediate time before they'll get any kind of help. Although I'm glad I came up in time before she stabbed herself, I think that if she had not done that and tried to overdose I don't believe that we would have even gotten in. There's no way because that's just how it works and you have to be in the middle of actually doing some kind of suicide, actually like lashing out at somebody physically. They have to see like proof. It would be like trying to prove battering or trying to prove like an assault and it would have to be actually in front of them for them to do something about it. So it got to that point.

All women as primary family caregivers of the chronically mentally ill should be included in the development of treatment and aftercare plans of their family members as well as in the planning and development of local mental health services. As Gail succinctly put it:

> There ought to be more communication. I think that there are gaps and doctors ought to be more involved with other family members in situations like this. I think that that's the fault of the medical profession. I know that there's a bit of confidentiality there and they think that you can't tell other family members but I think when you're a close-knit family and you're all together in the household, I think that the general practitioners ought to tell the others in that case.

Women as primary family caregivers of the chronically mentally ill and '[t]he family has a vested interest in the outcome of treatment... since the patient is likely to return home following this treatment. Families often are responsible for caring for the patient as an outpatient and making certain the patient takes medication and attends treatment sessions. However, families are generally involved only tangentially in the basic legal and ethical issues."

(Sadoff 1983:31) Involvement in the treatment and aftercare plans of family members and community support for women is essential to maintain and enhance their roles as primary family caregivers and state designated mental health promoters.

4.4 Mutual Help Groups

Six women reported attending mutual help groups[23] on a regular basis. All of these women reported that the groups were effective in helping them to manage some of the problems, issues and tensions created for women in their roles as primary caregivers and state designated mental health promoters of chronic manic depressives and schizoaffectives. These women reported that mutual help gave them a place to: 1) disclose, share and relate experiences with others 2) assist one another with information on how to recognize and manage the manic and depressive episodes of their chronic manic depressive and schizoaffective family members, which helps women deal with crisis and uncertainties 3) have access to newsletters and hot lines for women and 4) have access to information and referral services and educational programs.

Ingrid explained that attendance at a mutual help group provided a place to talk about problems and get support:

> ...to just talk with people. That's a great thing. It's somewhere you can talk to people. That's what you want so desperately to do, is talk....it was a great help for me meeting other people with the same kind of thing; having to cope with the same problems...and really before I went to...I just felt that I was alone in the world. I don't know... if I did know other people like this...it seems so common now, but it didn't

---

[23] The public tends to use "support group" as a generic term to refer to experiential peer led groups or professionally controlled groups or any and all varieties (Lavoie et al. 1994:xiv). Increasingly, researchers in the area use "support group" to refer primarily to professionally owned groups and to use self-help group, mutual help group or mutual aid self-help group to those that are primarily owned by consumers (Lavoie et al. 1994:xiv).

> then. It's a great support... and very nice families.

Diane revealed that attendance at a mutual help group provided a place to disclose mental illness in the family, make friends and find encouragement:

> You disclose in a way you do not disclose at work, I don't want to spill my guts out at work. These people have been down this road and they have tips, and if they don't have tips they have friendship and encouragement.

Nicole reported that attendance at a mutual help group provided a place to educate themselves and the family about chronic mental illness:

> It helped me because I got all the information from the pamphlets and papers. It taught me about the illness and how to deal with it. I could bring this information to educate family to better understand the illness.

Eleanor explained that attendance at a mutual help group provided a place to feel less alone, less helpless and less frightened

> ...I could talk to other people and sometimes you'd get little tips on how to handle the situation, mostly everybody had a sense of humor which really helped.... it made a very big difference because you feel so alone and so helpless, frightened and I think families must go through a lot of the same feelings as the patients themselves do.

However, Nicole also reported having to travel to Ottawa on a bi-monthly basis from rural Quebec to attend a mutual help group because "*[t]here is nothing in Manou*" in terms of mutual help groups. Sophie, also living in rural Quebec remarked that "*[t]here was nothing in Laduc*" and without transportation she remains unable to attend a mutual help group in Hull or Ottawa.

Lynda remarked *that "there's no organisation set up within the East Indian* *community in Toronto.*" Gail reported that "*I find it quite good. I find that once a month wasn't sufficient for my own needs. I find that I need more than once a month.* Mutual help groups are needed to expand to many rural areas where women as primary family caregivers are without support and resources. They are also are needed to represent the needs of diverse cultures where women as primary family caregivers are also without support and resources. These groups that exist in the present and future need to consider bi-monthly meetings and car pools for women who as primary family caregivers are without adequate support and resources.

Clearly, while these women suggest a beneficial role for the expansion of mutual help groups to assist all women with the crisis-like conditions and tensions emerging from social, political and economic forms of their oppression as primary family caregivers of the chronically mentally ill these groups are not accessible to all caregivers for reasons that include: overburden, location, stigmatization, culture and language. With the ongoing process of deinstitutionalization and the shift to community care, it is essential that the state strengthen services for women as primary family caregivers of the chronically mentally ill by expanding much needed community services such as respite care, twenty-four hour crisis hotlines, and community health, and mental health centre counselling, education, crisis intervention and mutual help groups. Chapter 5 concludes the study with recommendations for reforms and innovations on several fronts and suggestions for further sociological research on women as primary family caregivers of the chronically mentally ill using the effective model of a feminist political economy framework and Foucault's (1991:102) notion of governance.

5.0 CHAPTER FIVE: CONCLUSION

In concluding this study, I am mindful of a poem I read a year ago in Carleton University's *The Charlatan*---a poem written by Tess Van Straaten, a young woman who had grown up as a primary caregiver to a manic depressive father with schizophrenic tendencies:

Voices in his head

My father once told me
Something is to be said of those
who ride a tiger
a saying from his native bleeding Afrika

Bandaids of democracy cover her bloody broken bones
My father still bleeds

From the stronghold of schizophrenia
he screamed:
words hound, close around,
fencing us in

So-called sanity artificially restored,
my father told me I would learn from the sea
as it responds to the seagull's cry-
But he never did

In bouts of manic depression
he blamed evil in all the books piled up
so inviting but not invited

Doctors, pills, injections, the birth of my sister
made him well again
But you cannot bury disease,
it silently seeps into the watersystem

Messages from the Sanitarium read:
"Come tomorrow at the silencing hour,

between the moments, we'll meet the Music Master."
I never went

In spells of misdiagnosed agony
he lost one daughter and guilted the other-
an eleven-year blaming herself for mental illness

He wanted to silence the False Prophets
Yet was one himself

The last time I saw him,
My father stood on railway tracks-
trying to see infinite time,
trying to see if the future held hope

He wanted to build Jerusalem
in the ecosystem of his mind
But the evangelists are wrong-

You can find faith too late

March 21, 1996:16

As a sociologist and feminist who has also experienced primary family caregiving of two chronic manic depressive family members, I fear that many women as primary family caregivers and their chronically mentally ill family members living with inadequate support and resources such as Van Straaten and her father may one day say the same; that they too may one day "find faith too late." The caregivers in this study live a "common, and growing, nightmare." (Spears 1998:C1) As I have maintained throughout this study, the macro caregiving context has created significant problems, issues and tensions on a micro level for female family caregivers.

Together, the feminist political economy framework and Foucault's notion of governance have served as an effective analytical model in this study to reveal and help understand the problems, issues and tensions that women face on a micro level that include the never-ending burdens of caregiving, domestic and wage labour and, social isolation, stressed interpersonal relationships and stigma; the crises and uncertainties of abuse of the care recipient, abuse of the caregiver and, alcohol and drug abuse; the potential danger of chronically mentally ill family members to themselves and/or others; and family members frequent manic and depressive episodes and resistance to medical compliance, outpatient hospital treatment, hospitalization, monitoring and medical file information. These women try to manage the problems, issues and tensions, and the contradictions in their roles as primary family caregivers and as state designated mental health promoters through female family caregiver governance of family members with resistance from their family members. This resistance is facilitated by mental health legislation that safeguards the rights of chronically mentally ill family members as well, it is facilitated by the contradictory liberal rights and medical model discourses in mental health policy and legislation that in practice, reinforce the rights of the mentally ill both to receive and to refuse treatment.

What needs to be done to reduce these women's never-ending burdens of caregiving, domestic and wage labour and, social isolation, stressed interpersonal relationships and stigma? What needs to be done to reduce the crises and uncertainties of abuse of the care recipient, abuse of the caregiver, alcohol and drug abuse of the family member and, the potential danger of the family member to themselves and/or others? What needs to be done to reduce the challenges that these women face in the governance of their family members manic and depressive episodes, medical compliance, outpatient hospital treatment, hospitalization, monitoring and medical file information? What needs to be done to increase the chance that these women's problems, issues and tensions will be disclosed and detected? And what needs to be done to increase the effectiveness of the state and society's response to these urgent problems, issues and tensions?

The challenges are not simple. The solution will likely require a holistic approach with necessary reforms and innovations on several fronts that include: better understanding of the financial and personal reality of community care, the role of drug therapy and the balancing of rights and responsibilities among the state, caregivers and the chronically mentally ill. First, one important area of concern is medication. Lithium was approved by the American Food and Drug Administration for treating manic depression in 1970. Today, it remains the standard stabilizing treatment (Royal Ottawa Health Group 1997; Jamison 1995) despite its tremendous side effects and the fact that 30 to 40 per cent of manic depressives are lithium resistant (Duke and Hochman 1992:137). As this study found the majority of chronically mentally ill family members resist medical compliance because of negative side effects. It is frustrating that more effective treatments have not emerged in the past 20 years. Research on new drug therapies remains the responsibility of drug companies. These companies, whose primary concern is profit, have little reason to do further research. Hence we see how macro level structures related to treatment impact on micro level experiences with little or no means for people effected to create change.

Second, health and mental health policy and legislation are in need of major reforms. Clear operational definitions of "community care" which recognize the role of women as primary caregivers in conjunction with caregivers are utilized. These definitions must be reflected in health and mental health policy that addresses the needs of the chronically mentally ill and their female family caregivers. Current practices place them at risk.

Third, the state needs to actively recognize and reform the contradictory liberal rights and medical model discourses embedded within and between mental health policy and, the Canadian Charter of Rights and Freedoms, the Uniform Mental Health Act and provincial mental health legislation on the chronically mentally ill. There is a need for a balance of rights between the care recipient and the primary caregiver acting in the best interests of the chronically mentally ill family member. This is perhaps the most difficult issue to reconcile. Past abuse of psychiatric patients has demonstrated the problems of limiting patient rights. This study reveals the human costs of having no extraordinary limits. Finding a balance will be difficult but necessary.

Fourth, the state must recognize the problems, issues and tensions facing women as primary family caregivers of the chronically mentally ill and must provide support for those women. Non-intrusive, non-stigmatizing and supportive financial, educational, counseling and emotional assistance should be made more available to these women who indicate a need. Clear procedures need to be developed with, and, across sectors concerning how to arrange the necessary referral and other supports for women and their chronically mentally ill family members that include: social service agencies, advocacy organizations, health and mental health care providers, the police, and the legal profession. Governments should consider using funding and policy measures to ensure that the various organizations involved in assisting women and their chronically mentally ill family members make it a priority to recognize and address problems, issues and tensions in the family.

Fifth, family caregiver, advocacy and other organizations with a stake in the well-being of women as primary family caregivers should be encouraged and funded to mount community development initiatives that will break down the social isolation of these women. More advocates are needed in the community who are knowledgeable about what it means to be women and live as primary caregivers of the chronically mentally ill. These advocates can be informed about strategies to empower other caregivers and can play an essential public education role by raising awareness in the community about the prevalence, nature, causes and remedies of chronic mental illness in the family.

Sixth, women as primary caregivers of the chronically mentally ill also need access to education and training regarding chronic mental illness and how to respond to their family members. The same education and training has traditionally been required for workers in the social service, mental health care and the educational community. It provides workers with credentials that contribute to their knowledge being valued. These initiatives would empower participants not only to take reasonable steps to anticipate, detect, prevent and respond to the problem of chronic mental illness but also aid them in communicating and working with medical health professionals.

Finally, it is important that the communities who most need to be more informed of chronic mental illness and the family have access to the findings of current and future research. All academic research on the subject, after publication, should be worded in layperson terminology and widely disseminated where it is most needed in the community.

Sociologists and feminist researchers working in the social problems area must proclaim an ongoing committed, critical and radical role to both social change and social theory. More extensive research is required to further develop the theoretical and practical understanding of female family caregiving and the governance of madness and to build on the findings of this study. Feminist political economy and Foucault's notion of governance have proven useful for revealing not only the reality of community care but how private troubles reflect public/macro changes. As the macro-context changes we need to remain concerned first with the consequences for women and second with focusing on supporting primary caregivers for needed changes.

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APPENDIX A

STUDY QUESTIONNAIRE

As you know, I am conducting a study on the experiences of women as caregivers of chronic manic depressives. I'd like to begin with some general questions about you and the family member or members that you care for.

1- In what year were you born?

2- Were you born in Canada?
Prompts:
If no, where were you born?
When did you arrive in Canada?
How did it happen that you came to Canada?

3-Who in your family has ever been diagnosed with manic depression? Have you been and are you currently a caregiver for this family member or these family members with manic depression?

4-In what year was XXX (and XXX) born?

5-Was XXX (and XXX) born in Canada?
Prompts:
If no, where was XXX (and XXX) born?
When did XXX (and XXX) arrive in Canada?
How did it happen that XXX (and XXX) came to Canada?

6-Was XXX (and XXX) biological parents born in Canada?
Prompts:
If no, where were they born?
When did they arrive in Canada?
How did it happen that they came to Canada?

7-Were your biological parents born in Canada?
Prompts:
If no, where were they born?
When did they arrive in Canada?
How did it happen that they came to Canada?

8-In what city do you live?
Prompts:
Have you always lived in that city?

If no, how long have you lived in that city? Where else have you lived, when and for how long?

9-In what city does XXX (and XXX) live?
Prompts:
Has XXX (and XXX) always lived in that city?
If no, how long have they lived in that city? Where else have they lived, when and for how long?

10-Does XXX (and XXX) live in your household? If yes, for how long?
Prompts:
If no, for how long? What are the sources of XXX (and XXX) income?
Has this amount of income changed before and after the diagnosis of XXX (and XXX)?
Have the sources of income changed before and after the diagnosis of XXX (and XXX)?

11-Who else lives in you household?

12-What is the approximate annual income of your household?
Prompts:
What are the sources of this income?
Has this amount of income changed before and after the diagnosis of XXX (and XXX)?
Have the sources of income changed before and after the diagnosis of XXX (and XXX)?

13-What is the last year of education that you have completed?

14-What is the last year of education that XXX (and XXX) completed?

15-Are you employed?
Prompts:
If yes, what is your occupation?
How many hours a week do you work at your occupation both at home and at your job site?
Are you employed on a contract or permanent basis?

16-Is XXX (and XXX) employed?
Prompts:
If yes, what is XXX (and XXX) occupation?
How many hours a week does XXX (and XXX) work at his/her occupation both at home and at his/her job site?
Is XXX (and XXX) employed on a contract or permanent basis?

17-How religious are you?
Prompts:
If religious, do you attend a place of worship? [If yes, what place of worship and how

often]
Do you pray? [If yes, how often]
Are you involved in activities organized by or related to your place of worship? [If yes, what kind of activities and how often]?
Have you always been this involved in your religion?
Do your religious beliefs and/or activities help with how you manage the manic and depressive episodes of XXX (and XXX)?
If yes, when do you find that your religious beliefs and/or activities help with how you manage the manic and depressive episodes of XXX (and XXX)?
How do you find that your religious beliefs and/or activities help with how you manage the manic and depressive episodes of XXX (and XXX)?
Why do you feel that your religious beliefs and/or activities help with how you manage the manic and depressive episodes of XXX (and XXX)?

18-How religious is XXX (and XXX)?
Prompts:
If religious, does XXX (and XXX) attend a place of worship? [If yes, do you know what place of worship and how often]
Does XXX (and XXX) pray? [If yes, do you know how often]
Is XXX (and XXX) involved in activities organized by or related to this place of worship? [If yes, do you know what kind of activities and how often]?
Has XXX (and XXX) always been this involved in your religion?
Do you feel that XXX (and XXX) religious beliefs and/or activities help with him/her manage the manic and depressive episodes of XXX (and XXX)?
If yes, when do you think that XXX (and XXX) religious beliefs and/or activities help XXX (and XXX) with how s/he manages the manic and depressive episodes of XXX (and XXX)?
How do you find that XXX (and XXX) religious beliefs and/or activities help XXX (and XXX)with how s/he manages the manic and depressive episodes of XXX (and XXX)?
Why do you feel that XXX (and XXX) religious beliefs and/or activities help XXX (and XXX) with how s/he manages the manic and depressive episodes of XXX (and XXX)?

Now I would like to ask you about your experiences as a family caregiver of a chronic manic depressive or chronic manic depressives. What I am trying to do is understand family caregiving from a woman's point of view. I have some questions that I would like to ask you, but I want you to know that I believe that you are an expert in this area because it is you who give the care and you who knows what goes on between you and your family member(s). Because of this, please feel free to add any information that you believe is important that I don't ask about and please feel free to tell me if you think any of my questions aren't relevant or miss the point.

19-I was wondering, if anyone else in your family has been formally diagnosed as having a mental illness or if anyone else has experienced mental health problems?
Prompts:

If yes, who, for how long, with what, when was it diagnosed or symptoms showing, by whom was it diagnosed, is it being treated. how

20-When was XXX (and XXX) formally diagnosed with manic depression?
Prompts:
By whom? What were the events that took place that eventually lead to this diagnosis? What were the circumstances the month before, week before and on the day the diagnosis took place? Would you say that the manic and depressive episodes of XXX (and XXX) are controlled about the same, better or worse than before their diagnosis? Why, please explain.

21-What kind of responsibilities does caregiving for XXX (and XXX) consist of?

22-What ways do you organise your life to care for XXX (and XXX)?
Prompts:
Has caregiving for XXX (and XXX) affected your marriage ?
If yes, how (before and after diagnosis)
Has caregiving for XXX(and XXX) affected your relationships and friendships?
If yes, how (before and after diagnosis)
Has caregiving for XXX (and XXX) affected your health?
If yes, how (before and after diagnosis)
Has caregiving for XXX (and XXX) affected your income?
If yes, how (before and after diagnosis)
Has caregiving for XXX (and XXX) affected your work (unpaid and paid labour)?
If yes, how (before and after diagnosis)
Has caregiving for XXX (and XXX) affected your studies?
If yes, how (before and after diagnosis)
Has caregiving for XXX (and XXX) affected your family life?
If yes, how (before and after diagnosis)

23-What do you think would happen to XXX (and XXX) if you weren't there to help them?

Now I'd like to ask you some questions about the treatment of XXX (and XXX) for manic depression and your, XXX's (and XXX's) uses of services in the community.

24-Is XXX (and XXX) currently taking prescribed medication for manic depression? If no,
did XXX (and XXX) ever take prescribed medication for manic depression? Why did they stop? How else is it being treated?
Prompts:
If yes, how is it being treated? Are you or were you ever in contact with any of the professionals, psychiatrist, physician and/or therapist treating XXX (and XXX) manic depression? If yes, for how long are and/or were you in contact? Can you please tell me

about this. Does this contact help or hinder the control of their manic and depressive episodes? How? What did you say and/or do during this contact? How? How does XXX (and XXX) respond to this contact? What ideally would you like to do about this contact with psychiatrist, physician and/or therapist treating XXX (and XXX) manic depression? Do you think your family member takes their medication for their manic depression regularly as prescribed? What makes you think that? If no, what do you say and/or do about it? How does XXX (and XXX) respond to this? Have you ever experienced problems with XXX (and XXX) around the issue of them taking their medication for manic depression regularly? If yes, what do you say and/or do and how does XXX (and XXX) respond to this? What ideally would you like to do about them not taking their medication for manic depression regularly? Has their medication changed over the time of their diagnosis? If yes, how many times? Why? Has this helped or hinder the control of their manic and depressive episodes?

25-Do you know if XXX (and XXX) sees their psychiatrist, physician and/or therapist about their manic depression as regularly as you feel they should?
Prompts:
If no, can you tell me why they do not? What do say and/or do about it? How does XXX (and XXX) respond to this? What ideally would you like to do about them not seeing their psychiatrist, physician and/or therapist about their manic depression as regularly as you feel they should? Has this changed over the time of their diagnosis? If yes, how? Why? Has this helped or hinder the control of their manic and depressive episodes?

26-Do you know if XXX (and XXX) sees their psychiatrist, physician and/or therapist about their manic depression as regularly as XXX (and XXX) feels s/he needs this care?
Prompts:
If no, can you tell me why not? What do say and/or do about it? How does XXX (and XXX) respond to this? What ideally would you like to do about how XXX (and XXX) feels about the need for this care? Has this changed over the time of their diagnosis? If yes, how? Why? Has this helped or hinder the control of their manic and depressive episodes?

27-Has XXX (and XXX) willingness to see their psychiatrist, physician and/or therapist about their manic depression changed over the time of diagnosis?
Prompts:
If yes, can you tell me why you think this has occurred? What do say and/or do about it? How does XXX (and XXX) respond to this? What ideally would you like to do about it? Has this changed over the time of their diagnosis? If yes, how? Why? Has this helped or hinder the control of their manic and depressive episodes?

28-Has XXX (and XXX) psychiatrist, physician and/or therapist changed over the time of their diagnosis?
Prompts:
If yes, how many times and why? What do you say and/or do about it and how does XXX

(and XXX) respond to these changes? What ideally would you like to do about it? Has these changes helped or hinder the control of their manic and depressive episodes?

29-Has XXX (and XXX) ever been in trouble with the police?
Prompts:
If yes, when? In what city? What happened?
How did you find out? What do say and/or do about it? How does XXX (and XXX) respond to this? What ideally would you like to do about it?

30-Was XXX (and XXX) ever taken or have they voluntarily gone to an emergency hospital room for their manic depression? [if no, have either of you considered this as an option, why or why not, tell me about this, do you think do you this would help? who and how do you think this would help]
Prompts:
If yes, in what city did they go to an emergency hospital room? What were the circumstances that lead to this?
To date, do you know how many times have they gone to an emergency hospital room for their manic depression?
To date, how many times have you taken them?
What do say and/or do about it? How does XXX (and XXX) respond to this? What ideally would you like to do about it?
Do you feel this helps? When and how?

31-Was XXX (and XXX) ever hospitalised for their manic depression? [if no, have either of you considered this as an option, why or why not, tell me about this, do you think do you this would help? who and how do you think this would help]
If yes, in what city were they hospitalised? What were the circumstances that lead to this?
To date, do you know how many times and for how long they have been hospitalised for their manic depression? Have they experienced 0-4, 5-9, 10-14, 15-19 etc. hospitalizations per year?
Before and after diagnosis?
What do say and/or do about it? How does XXX (and XXX) respond to this? What ideally would you like to do about it? Do you feel this helps? When and how?

32- Can you tell me about your views towards permanent institutionalisation of chronic manic depressive family members as a means of managing their manic and depressive episodes?
Prompts: What length of time do you consider to be long term institutionalisation of chronic manic depressive family members? What are your views towards long term institutionalisation of chronic manic depressive family members as a means of managing their manic and depressive episodes?
What length of time do you consider to be short term institutionalization of chronic manic depressive family members? What are your views towards short term institutionalisation of chronic manic depressive family members as a means of managing their manic and

depressive episodes?
Can you tell me about your views towards having chronic manic depressive family members reside at home with family as a means of managing their manic and depressive episodes as an alternative to institutionalisation? For chronic manic depressives what do you recommend as a living arrangement, at this point given your experiences? Why? Is living at home with family members a suitable living arrangement for chronic manic depressives? Why?

33-Has XXX (and XXX) ever been or is s/he currently involved in any outpatient activities or programs with a hospital? [If no, have either of you considered this option, why or why not, tell me about this, do you think do you this would help? who and how do you think this would help]
Prompts:
If yes, in what city? Tell me about this experience? How and who do you think this has helped?

34-Have you, XXX (and/or XXX) ever attended a family support group in the community? [If no, have either of you considered this option, why or why not, tell me about this, do you think do you this would help? who and how do you think this would help]
Prompts:
If yes, in what city? Tell me about this experience. how and who do you think this has helped?

35-Have you, (and/or XXX) ever used a crisis or distress phone-in centre when trying to manage the manic and depressive episodes of XXX (and XXX)? [If no, have either of you considered this option, why or why not. tell me about this. do you think do you this would help? who and how do you think this would help]
Prompts:
If yes, in what city? Tell me about this experience. how and who do you think this has helped?

36-Do you think it is important to take medication to control the manic and depressive episodes of manic depression?
Prompts:
Why or why not?

37-Do you think it is important to see a therapist, physician and/or psychiatrist to control the manic and depressive episodes of manic depression?
Prompts:
Why or why not?

Now I/d like to ask you some questions about your relationship with XXX (and XXX).

38-Can you tell me what your relationship with XXX (and XXX) has been like before and after his/her diagnosis?
Do you see or hear from them often? Tell me about the time you spend together?

39-Can you tell me about a typical day when you are dealing with XXX (and XXX)?
Prompts:
How do you organise your daily activities around caring for XXX (and XXX)?

40-Have you ever been abused by XXX (and XXX)or have your ever abused XXX (and XXX)?
Prompts:
If yes, when? What happened?
What did you say and/or do? How did XXX (and XXX) respond?

I'd like to ask you some questions about the depressive episodes of XXX (and XXX).

41- What kinds of feelings does XXX (and XXX) experience during their depressive episodes? [feeling sad, low blue, hopeless, helpless, useless, guilty, ashamed and remorseful] What kinds of behaviours does XXX (and XXX) exhibit during their depressive episodes?] What kinds of appearances does XXX (and XXX) display during their depressive episodes?
What do they say, do and appear like? What do you say and/or do? How do XXX (and XXX) respond?

42-Do you experience confrontations around how to deal with or respond to the feelings they experience, the behaviours they exhibit or the appearances they display during their depressive episodes? Can you tell me about this?

I'd like to ask you some questions about the manic episodes of XXX (and XXX).

43- What kinds of feelings does XXX (and XXX) experience during their manic episodes?
[very elevated mood, feeling high, overactive, elated, euphoric and ecstatic] What kinds of behaviours does XXX (and XXX) exhibit during their manic episodes?] What kinds of appearances does XXX (and XXX) display during their manic episodes? What do they say, do and appear like? What do you say and/or do? How do XXX (and XXX) respond?

44-Can you tell me approximately how many manic and depressive episodes that XXX (and XXX) experience every year, before and after diagnosis?
Prompts:
Do they experience 0-4, 5-9, 10-14, 15-19 etc. manic and depressive episodes per year?
Before and after diagnosis?

45- Do you experience confrontations around how to deal with or respond to the feelings they experience, the behaviours they exhibit or the appearances they display during their manic episodes? Can you tell me about this?

46-Has XXX (and XXX) ever tried to physically harm their body, themselves and/or others?
Prompts:
If yes, when? In what city? What happened? How did you find out? What did you do? What kind of support did you have from family, friends, police and hospital? Can you tell me why you think this has occurred? What did you say and/or do about it? How does XXX (and XXX) respond to this? What ideally would you like to do about it?

47-Has XXX (and XXX) ever tried to commit suicide?
Prompts:
When? In what city? What happened?
How did you find out?
What did you do?
What kind of support did you have from family, friends, police and hospital? Can you tell me why you think this has occurred? What did you say and/or do about it? How does XXX (and XXX) respond to this? What ideally would you like to do about it?
What if anything can be done to prevent suicides of manic depressive family members?
Is there anything that family caregivers can do to prevent suicides of manic depressive family members?
Is there anything that manic depressives themselves can do to prevent their own suicide?

I have final question to ask before we finish this interview.

48-Are there any resources that have helped you, XXX (and XXX) before and after their diagnosis?
Prompts:
When did these resources help? In what city? How do you feel they helped? Why do you feel they helped? To To date, what additional resources could have helped you, XXX (and XXX) manage the manic and depressive episodes of XXX (and XXX)? Who should be responsible for the expansion and/or creation of these resources?

Thank you for your participation in this study. You will receive a summary of the results of this study once it has been defended and your responses will help to broaden current research on the
experiences of family caregivers of mental illness with a view to proposing recommendations that will facilitate this caregiving process.

APPENDIX B

INTERVIEW ADVERTISEMENT

Are you a woman who is a primary family caregiver of a chronic manic depressive?

If yes ---

Would you be willing to share your confidential and anonymous experiences with a researcher for a university study?

If yes ---

I am seeking women as primary family caregivers of chronic manic depressives to take part in a M.A. thesis study on their qualitative experiences. The interview will not exceed 2.5 hours and will take place in a safe location of your choice. Through the interview process, you may choose not to answer the given question(s) and you may terminate the interview or withdraw from the study at any time you wish to do so, without penalty. As well, as a participant, you will be provided with a summary of the results of this study after the thesis defense. With regard to confidentiality and anonymity, the researcher will take the following steps: the researcher will erase each interview tape after the thesis defense or at your request, they will be returned to you after the thesis defense; the researcher will eliminate any identifying information from the transcripts of the interview, from the thesis product, and from any speeches, research, articles or books not yet written or published; and although you will be asked to sign a consent form, the researcher will destroy this form or at your request, it will be returned to you after the thesis defense. For more information on taking part in this study please contact Lisa at 746-9474.

APPENDIX C

CARLETON UNIVERSITY ETHICS COMMITTEE CLEARANCE

Carleton
UNIVERSITY

Office of Research Services

memorandum

DATE: November 22, 1996

TO: Lisa J. Hanna
Dept. of Sociology and Anthropology

FROM: Anne Burgess
Director of Research Services

RE: **Your application for ethics clearance**

Your application has been reviewed by the Carleton University Ethics Committee, and your proposal ("Manic Depression, Female Family Caregivers, and the Governance of Madness") has been found to be ethically acceptable.

The Committee, in giving this decision, asked that you 1) retain the tapes in a securely locked cabinet until they are erased/returned; and 2) that you retain the transcripts, with no identifying information, in a securely locked cabinet, for a reasonable amount of time. (They are the database on which conclusions are made.)

Anne Burgess
A.B.

c.c. Prof. K. Kelly
c.c. Prof. Hugh Armstrong

APPENDIX D

LETTER OF CONSENT

This is to acknowledge that I understand that the study that I am agreeing to participate in is on the qualitative experiences of female family caregivers of chronic manic depressives. This study is being conducted by Lisa J. Hanna, in partial fulfilment of the requirements for the master or arts degree in sociology, in the Department of Sociology and Anthropology at Carleton University. I have been assured by the researcher that my interview for this study is completely voluntary, that this interview will not exceed 2.5 hours and that it will take place in a safe location of my choice. I have also been informed of my right not to answer any given question(s) and that I may terminate the interview or withdraw from the study at any time should I wish to do so, without penalty. The researcher will provide me with a summary of the results of this study after the thesis defence.

With regard to confidentiality, I understand that the following precautions will be taken by the researcher: the researcher will erase each interview tape after the thesis defence or at my request, they will be returned to me after the thesis defence; the researcher will retain the tapes in a securely locked cabinet until they are erased/returned; the transcripts of the tapes will be retained with no identifying information, in a securely locked cabinet, for a reasonable amount of time decided by the principal researcher of this study; the researcher will eliminate any identifying information from the transcripts of this interview, from the thesis product, and from any speeches, research, articles or books not yet written or published; and although I will be asked to sign this informed consent form, the researcher will destroy this form or at my request, it will be returned to me after the thesis defence.

In the event that I have questions or concerns about this interview process I may contact the supervisor of this study, Dr. Katharine Kelly (613) 520-2600 ext. 2624, Department of Sociology and Anthropology, Carleton University.

Date: ____________________

Respondent: ____________________

Interviewer: ____________________

APPENDIX E

A POST-INTERVIEW LETTER OF THANKS FROM THE RESEARCHER (LISA J. HANNA)

Thank you for participating in the study that I am conducting on the experiences of women as primary family caregivers of chronic manic depressives. I will be contacting you in a confidential and discreet manner by phone so that I can arrange for you to receive a summary of the results of this study once it has been defended in the Spring or Summer of 1997. Your responses will help to assist other families through the broadening of current research on manic depression and the family as well, the results of this study will allow for further recommendations to mental health policy and services on a federal and provincial level.

COMMUNITY RESOURCES AVAILABLE TO ASSIST FAMILY MEMBERS WITH THE CHALLENGES OF MENTAL HEALTH PROBLEMS

The following is a list of select resources available in the city of Ottawa to assist you with nay questions and concerns that you may have in the management of mental health problems in your family. If you do not reside in the city of Ottawa and require assistance with any questions and concerns that you may have about the management of mental health problems in your family these resources will be able to direct you to other services available in your city.

The Canadian Mental Health Association (Ottawa - Carleton Branch) fosters community acceptance, works to improve availability of services for people with mental health problems and their families, and promote integration. For more information contact: (613) 737-7791

Depression, Manic Depression Mutual Support Group is a local organization serving the national capitol area. Dedicated to all who have experienced depression or manic-depression, their families and friends, or others interested in mutual support for people affected by mood disorders. DMD's goal is to help one another cope, provide information on the nature of mood disorders, and foster public awareness. Telephone (613) 526-5406 for information (24 hour information hotline - recorded message)

Ottawa Distress Centre 24 hours a day, 7 days a week, someone answers the phone and provides confidential help - befriending, crisis intervention, referrals.
Telephone: (613)238-3311

Royal Ottawa Hospital Social workers offer information and support to family members and friends who have mental health problems. Contact the following individuals for more information: Jo Weston, M.S.W., C.S.W. (613) 722-6521 (ext.6256) or

Virginia Lafond, M.S.W., C.S.W (613) 722-6521 (ext. 6610) or
Marian Hallick, (613) 722-6521 (ext. 6360) or
Donna Horner (613) 722-6521 (ext. 6421)

APPENDIX F

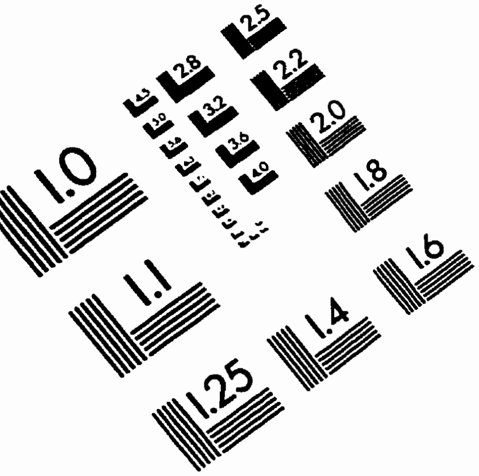
CONTRACTUAL AGREEMENT WITH TRANSCRIBER

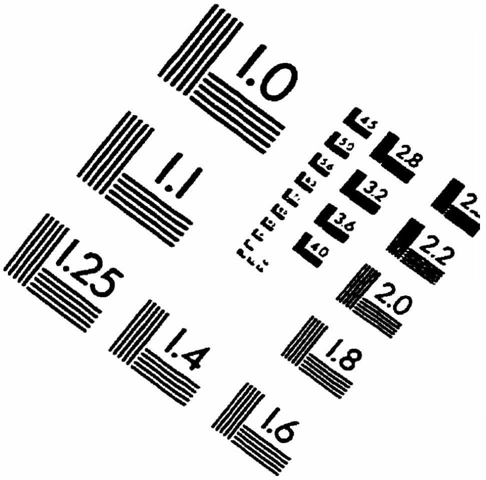
This is to acknowledge that I understand, as the sole transcriber of the interview tapes belonging to Lisa J. Hanna's study on the qualitative experiences of female family caregivers of chronic manic depressives, conducted in partial fulfilment of the requirements for the master of arts degree in sociology, in the Department of Sociology and Anthropology at Carleton University that I am required to take the following precautions with regard to confidentiality and anonymity: all research content and matter related to these tapes, to the transcripts on diskette and to the overall study will be kept strictly confidential both during and after the period of transcription to ensure confidentiality and anonymity to all participants in the study; through the duration of the transcription of the original interview tapes, both the original tapes and the transcripts on diskette will be retained with no identifying information, in a securely locked cabinet until they are returned to the researcher; I will not keep in my possession any other copies of these original interview tapes except for the original interview tapes and the original transcripts on diskette in my possession through the duration of the transcription and will return all original interview tapes and original transcripts on diskette to the researcher; in the event that the transcription is completed or terminated for any reason, I will not keep in my possession any copies of these original interview tapes in any form and will return all original interview tapes and all original transcripts on diskette.

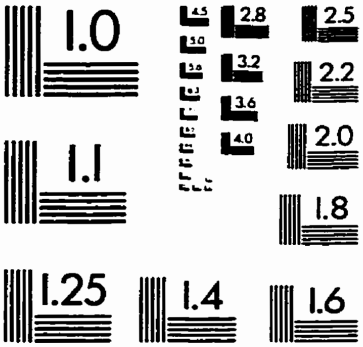
Date: ________________ Transcriber: ____________________

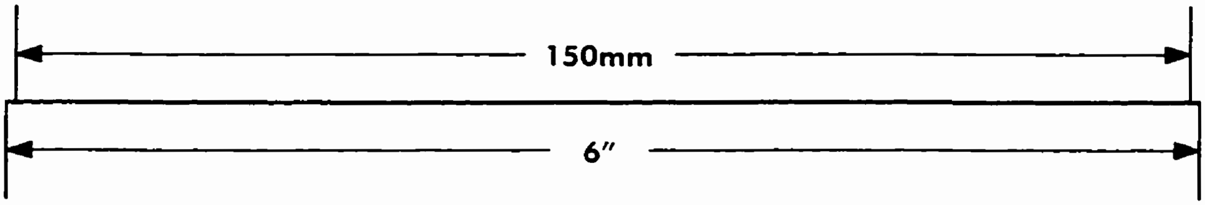
Principal Researcher: ______________

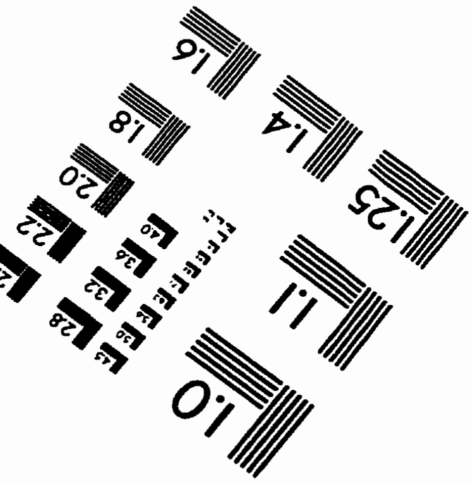
IMAGE EVALUATION
TEST TARGET (QA-3)

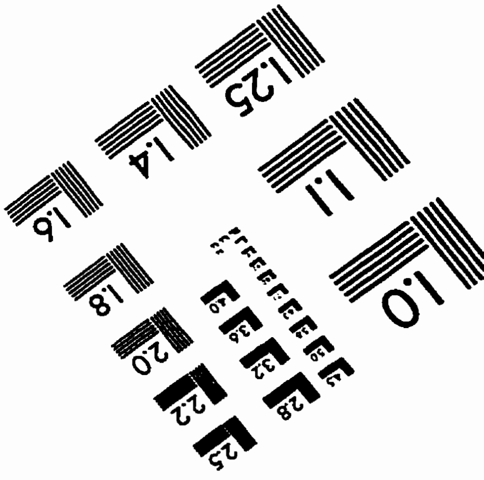












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