"YOUNG CARERS" OF PARENTS WITH MENTAL HEALTH ISSUES

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B.S.W. Honors in Social Work (University of Western Ontario)

A Thesis

Submitted to the School of Graduate Studies

in Partial Fulfillment of the Requirements

for the Degree

Master of Social Work

McMaster University

MASTER OF SOCIAL WORK   **McMaster University**
(2011)   **Hamilton, Ontario**

TITLE: **"Young Carers" Of a Parent with Mental Health Issues**

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NUMBER OF PAGES: **vi, 75**

ABSTRACT

It is estimated that twenty percent of the Canadian population experiences a serious mental illness at some point in their lifetime. A portion of those that do so will be parents. Research indicates that in some circumstances, when a parent with a serious mental illness needs support that they are not getting from other adults or the formal mental health care system, the caregiving responsibilities can fall to their children. Sometimes called "young carers" in literature developed in the U.K. and elsewhere, there has been little attention in Canada to this population or the implications of the term "young carers". Through a critical feminist lens, a small qualitative study was undertaken to explore the lived experiences of adults looking back on having been "young carers", a perspective seldom taken in the literature.

The four study participants had all cared for their mothers in households with extended social networks that included fathers and siblings- an interesting counterpoint to the "young carer" literature, which has centered on isolated single parents with children. Participants described how they found themselves in caring roles, what their caring consisted of, and why they continued to care despite other options being available. The study reveals the intricate social pressures that the participants faced, and suggests that becoming a carer may be more complex than past studies have indicated. I examined participants' stories with an eye to the structural forces that shaped their pathways as carers and their reflections on those pathways. The discussion focuses on what the participants' experiences can tell us about the contemporary neoliberal political climate: how its emphases on individualism, independence and smaller government, contribute to the depletion of public mental health services and a troubling focus on sustaining "young carers" rather than questioning their positioning.

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INTRODUCTION

I realized early in my social work education that whether or not I practiced in areas that were deeply personal to me, the issues from these areas would always be an undeniable part of my life. For me, this deeply personal area is mental health, as I was - and still am to some degree- a primary care giver for a parent with a serious mental health issue. When I considered the choices for the broad topic of my graduate thesis, caring for a parent with a mental health issue was an obvious selection. Prior to this year, I had done a fair bit of research on the topic of "young carers" - or people who are under the age of eighteen who provide a significant amount of care for a family member. This topic has been widely researched in the United Kingdom and more recently has been growing in Australia. I learned that these young people took on a caring role because they did not have other choices, and as a result they had to carry the burden of providing support for their parent (Aldridge & Becker, 1993).

I felt that this literature demonized the person needing support or the "dependent" as they were referred to, especially if the "dependent" was a parent and it was their child providing them care. This literature suggests that when children provide care for their parent there is role reversal where the child parents their parent (O'Dell et al. 2010). This construction can have dangerous implications in leading to judgments parental incapacity and the needs for child protection (Edwards, 1995; Stanley et al. 2003). I did not think that I experienced a burden by providing care to my parent, and I felt that in many ways, I was better off than my friend down the street whose parents fought every night. I

wondered if I felt better off because I had another parent who was not in contact with the mental health care system, or because we were financially privileged.

As I researched more into the topic I discovered a body of literature that critiqued "young carer" research for its assumptions regarding traditional carer-dependent relationships, the Westernized ideal of childhood, and its lack of attention to contextual factors (Henderson & Forbat, 2002; O'Dell et al. 2010). Resonating with my own questions, these critiques suggested that research on "young carers" should draw attention to the needs of individuals needing support, and the insufficiency of the services available provided to them (Keith & Morris, 1995).

As I continued researching I returned to my interest in young people who provide care for a parent in contact with the mental health care system. This is rarely studied in young carer literature, which takes up issues of children who provide care for a parent with a physical disability. Preliminary studies show that young people who provide care for a parent in contact with the mental health care system are different from other types of carers (Aldridge, 2006). It is suggested that these young people take on high emotional caring responsibilities rather than material or physical. The emotional responsibilities in a mental health caring context are unique to the general group of young people who care, and can include monitoring and assessing their parents' mental health status (Aldridge, 2006). There is also a high level of stigmatization associated with mental health that leaves individuals in contact with the mental health care system and their informal carers at a disadvantage. Young people assuming the role of a carer are found to be especially vulnerable due to their age and possible lack of financial resources (Scheyett, 2006).

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The concept of "young carers" has been taken up only recently in Canada – a fact that suggests it is an important time to contribute to this literature. The small qualitative study reported here was designed to explore the experiences of young people who provide care for parents in contact with the mental health care system, and what their experiences tell us about the taken for granted assumptions in the dominant "young carer" discourse. The study invited participation from people, now adults, who had provided care for parents when they were younger. This perspective has been seldom explored in "young carer" literature, and was taken as it would seem that individuals who are now adults can provide unique insights into their past (Aldridge, 2006; Olsen, 1996).

1.0 LITERATURE REVIEW

I began my exploration researching "young carer" literature from Britain and Australia, in order to understand how the topic had been shared and understood. I soon realized that the topic of "young carers" and more broadly informal care, reached into many areas of academic study. The critiques of the "young carer" paradigm came primarily from disability scholars, and critical social policy. As I wrestled with complex social impacts I relied heavily on feminist research methodology and literature.

This literature review begins by situating the study in Ontario, and gives a brief description of the mental health care system and the community reforms that underlie its current operation (Brodie, 2002). A consequence of these reforms has been the widespread transfer of care from paid professionals to informal carers. The informal care sector in mental health has increasingly been acknowledged by both research and policy makers as providing a substantial amount of the total care given to individuals connected with the system (Henderson, 2005; Teghtsoonian, 2009). This literature review focuses on a sub-group of informal carers labeled "young carers" by British researchers. "Young Carers" are individuals, under the age of eighteen, who take on the responsibility for caring for a family member (Aldridge, 2006).

The development and lived experiences of "young carers" as a general group is explored and as well as the responses that have been developed to support this group. "Young Carers" have been deemed to be "at risk" for detrimental outcomes, because it is believed that they take responsibilities that are inappropriate for their age and developmental stage (Becker, 2007). A critique is then provided about the existing

"young carer" literature and suggests that this research produces support for "young carers" that ensures the informal caring system doesn't break down. This literature review ties the topic of the faltering mental health care system in Ontario with a specific group of "young carers" who provide informal care to a parent who is in contact with the mental health care system.

1.1 The Mental Health Care System in Ontario

Over the past three decades, the provincial government in Ontario has introduced health care reforms that rely heavily on the involvement of unpaid carers. Much of the policy relating to health care is provincial, though these reforms have been a national trend perpetuated by the neoliberal political ideology that currently dominates the Canadian public sphere (Brodie, 2002). The core element of neo-liberalism is that the state is able to govern individuals in society at a distance through endorsing personal choice, instead of direct political control. When the government operates by supporting personal choice and an individual ends up in need, it can be rationalized that it was their own fault, and not that of the state (Teghtsoonian, 2009).

This has been of particular significance for individuals involved in the mental health care system; a system that engages with a highly stigmatized population and that was already poorly funded prior to the restructuring (Henderson & Forbat, 2002). In mental health care, the reforms involved a process of deinstitutionalization in which there was a shift from institutional care to community care (Sealy & Whitehead, 2004). The goal of deinstitutionalization was to cut government costs while increasing quality of life

by supporting individuals in contact with the mental health system to participate in their communities. The shift to community mental health care thus far has been largely underfunded by the government and deemed unsuccessful as a result (Sealy & Whitehead, 2004). These dynamics - a policy rhetoric of community care, unaccompanied by adequate public resources - have been enforced in many Western jurisdictions, not only in Canada (Teghtsoonian, 2009).

Although there is not enough support in the community, the goal of the current mental health care system is to discourage costly institutional service dependency and encourage individual families to replace professional support with informal care (Teghtsoonian, 2009). Using this rationale, informal care can be exploited as part of a family "duty" founded on love and attachment, creating an assumed understanding that care is given willingly and free of charge (Becker, 2007). It is suggested that mental health care's foundation is now based on the contribution by unpaid, informal carers, saving governments' millions of dollars every year (Henderson & Forbat, 2002). What is less spoken about is they fact that this small "army" of informal carers is overwhelmingly made up of women (Kittay, 1999). Women, who historically have provided care for all forms of "dependents" including their children, elderly parents, or ill family members, must put their own desires and interests aside in order to do so. Feminist critiques have highlighted that while women are caregivers, their participation in paid employment and the public sphere is constrained and gender inequalities are sustained and deepened (Kittay, 1999).

1.2 Young Individuals Who Provide Informal Care

The meanings and consequences of this transfer from paid professionals to informal caregivers in the mental health care system has been the focus of considerable theoretical and research attention (Keith & Morris, 1995; Kittay, 1999). The experiences of a sub-group among them, "young carers" has been less studied in general and has been barely explored in Canada. This section will discuss the development of the "young carer" category in practice and research, and how the research methods to explore the lives of "young carers" have changed over time (Aldridge & Becker, 1993). The results of "young carer" research projects will be discussed, as well as their impacts in local and global communities (Becker, 2007).

"Young Carers" as A New Construction: Research Development

In the early 1990's social service professionals in the United Kingdom began to notice that young people were often providing informal care to their parents, siblings or other relatives. This occurred when their family member lived with chronic conditions such as brain injuries, substance abuse problems, physical or developmental disabilities, or dementia (Aldridge & Becker, 1993). Studies were undertaken to conceptualize who these young people were, and how many of them existed in society. These studies revealed that there were a large number of young people who provided care, though often "hidden" or unidentified. This was found to be due to the fact that young people did not often identify themselves as "carers" and they may have also feared embarrassment of stigmatization over their role (Smyth, Blaxland, & Cass, 2011). Subsequently,

researchers became aware of the fact that young people who provide care may be suffering, as they were taking on large amounts of responsibility and their needs were generally ignored by service professionals who did not see them as their primary clients (Aldridge & Becker, 1993).

Research about young people providing care occurred within a larger social movement and research emphasis in the United Kingdom. This social movement was concerned that the rights and needs of informal carers were not being recognized by the public or government, and that informal care sustained inadequate formal care. Like Canada, the United States, and Australia, the UK experienced fiscally conservative governments in the late 1980's that pushed community reforms. These community reforms resulted in an increase of unpaid informal care, and were the object of vigorous feminist critique (Lloyd, 2006). The combination of this "Informal Caregiver" movement and mainstream media interest in child welfare pushed the issue of young people who provide care into the attention of prominent research institutions (Lloyd, 2006). Findings from the initial studies raised many issues regarding children's rights and welfare in situations where they were providing care for an adult. The level of care that some young people provided was deemed to be "inappropriate" for their age and it was feared that these young people would suffer in relation to their peers. Further studies conducted to determine the amount and description of responsibilities these young people carried and with what consequences for their quality of life (Gays, 2000).

Most recent research has focused on the needs of these young people, and how professionals and social services can support them in their role (Grant, Repper & Nolan,

2002; Stanley, Penhale, Riordan, Barbour & Holden, 2003). The literature originating from the United Kingdom named young individuals who provide care as "young carers", and this term was quickly taken up by other researchers globally. This literature review explores the way the term "young carer" has been constructed through research and policy (Keith & Morris, 1995). There is no globally agreed upon definition of the term but the most common standard used recognizes "young carers" as:

> *Children and young persons under 18 who provide or intend to provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult.* (Becker, 2007, pg. 25)

In the Canadian context, the study of "young carers" is in its infancy, as there have only been a handful of research projects that explore this specific issue (Young Carers Initiative Niagara, 2005).

"Young Carer" Research Methodologies

The original studies of "young carers" attempted to quantify the existence of this social group. This was most often achieved through small-scale projects that tried to statistically extrapolate the number of "young carers" in a given area (Aldridge & Becker, 1993). Although these studies produced a wide range of conflicting numbers causing most of the results to not be seen as evidence, media and public interest fueled more research that insisted "young carers" were increasing (Keith & Morris, 1995). Researchers found that surveys and questionnaires were unsuccessful in this context as

they limited expression and explanation that young people could give regarding their circumstances. Qualitative studies using in-depth, semi-structured one-on-one interviews with young people in caregiving roles were needed to capture the voices of these young people. It is for this reason that qualitative research methods have been heavily used to the present day in this research area (Aldridge, 2006).

Despite the recent push for quantitative evidence, there is only a limited body of research that attempts to quantify caring experiences, and perceived stress in young carers. There have also been comparative studies that examine the differences between young carers and their peers (Early et al. 2006). Research methods exploring the lived experience of "young carers" have also provided the perspectives of all individuals involved to gain a fuller picture of the issue. Although the research primarily aims to gain insight into the lives of "young carers" by interviewing the young persons themselves, it has also been found useful to examine the perspective of the individuals to whom the young persons are providing support, as well as the perspective of that individual themselves (Gray, Robinson & Seddon, 2008).

Results of "Young Carer" Research Projects

Although there has not been an abundance of Canadian research, it is reasonable to consider that many of the results of research undertaken in comparable contexts (UK, Australia) will be transferable to the Canadian context. My review suggests that the literature reports findings in three broad areas: (1) young people's experience of caregiving; (2) the consequences of these caregiving responsibilities; and (3) what can be

done to support these young people (Becker, 2007; Moore & McArthur, 2007; Gray et al. 2008).

In regards to the first area explored in "young carer" research, certain factors have been speculated to influence whether a young person is likely to take on caring responsibilities. These factors include: a young person's gender (being female), and having a mother who requires support who is a lone parent and is not in paid work. Other factors include the fact that children are able to care due to co-residency, and because of their willingness and loyalty to help their family members (Aldridge, 2006). Many studies have explored what it means to be "young carers" on a day-to-day basis. These studies reveal that young people take on a variety of caring tasks that range from physical and material to emotional. An example of a physical task may come in the form of assisting a sister out of bed, whereas an example of a material task may be grocery shopping. Emotional tasks on the other hand, can take the form of cheering up a parent who is feeling depressed (Moore & McArthur, 2007).

With respect to the possible consequences of a young individual taking on the responsibility of providing significant levels of care, research suggests that having household responsibilities like weekly chores may have a positive effective on a young person's development. However, the research on "young carers" suggests that the frequency and type of care that a "young carer" delivers may be "inappropriate" or " not normal" for the young person's age (Early et al. 2006). It is suggested these caregiving responsibilities can be so severe that there is a role reversal, and in the case of young people caring for their parent, they actually end up "parenting" their parent (Keith &

Morris, 1995). Some of the negative outcomes thought to be associated with this level of inappropriate responsibilities have been found to include: "Poor school attendance, loss of social opportunities, impact on future plans and independence, bullying, social stigmatization, and isolation" (Early et al. 2006, pg. 171). Studies that highlight the negative outcomes of caring have affirmed the "burden of care" or "risk" discourse that has often been attached to conceptualizations of "young carers". Competing with this "burden of care" discourse is the resilience discourse, which suggests, in contrast, that young people providing care will develop high levels of maturity and superior coping skills (Gladstone, Boydell, McKeever, 2006).

When policy makers and program developers began to work on supports that could help young people providing care, their responses tended to focus on the former: on relieving the "burden of care". This led to the development of programs that gave respite, offered social connection with peers in similar situations, and counseling services (Becker, 2007). In the United Kingdom, there was a successful social movement that resulted in the inclusion of "young carers" in *Carer's Recognition & Services Act* of 1995. For example in British Department of Health (2000) policy "young carers" are specifically mentioned as a group that workers should watch for, and also gives them guidance and best practice methods for working with this group. The UK is the only jurisdiction where "young carers" are included in legislation, although Australia is close to achieving similar end goals (Becker, 2007). Most recently "young carer" research is shifting its focus to recognize the needs of each family member living with the individual

who is in contact with a social service system (Gladstone et al. 2006; Moore & McArthur, 2007).

1.3 A Critique of the Research Focus on "Young Carers"

Despite the growing base of knowledge about "young carers" that has spread from the United Kingdom to Australia and the United States, there is a small body of literature that is wary of the results and implications of the "young carer" research and the practices and policies that flow from it (Keith & Morris, 1995; Lloyd, 2006; Olsen, 1996). It is very important to take these critiques into consideration as Canadian researchers will take up these ideas and apply them to studying young people who provide care locally (Young Carer's Initiative Niagara, 2005). These critiques problematized the assumptions that the dominant literature on "young carers" makes regarding: caring relationships, westernized ideas of childhood, and (the inattention to gaps of missing) contextual factors. Many of these critiques are rooted in the disability movement, which takes the position that the concept and practice of supporting "young carers" as it exists currently can undermine parental capacity and does not address the real problem and its structural roots (Davis, 1995; Keith & Morris, 1995).

The Neo-liberal Carer-Dependent Relationship

The first theme of critique suggests that studies of "young carers" assume the young person involved in a carer-dependent relationship that is solely constructed by neo-liberal ideology (Henderson & Forbat, 2002). In Canadian society, the relationship

between an individual who needs care - the "dependent"- and the individual who provides care is constructed in a very specific way. This construction is framed by the neo-liberal prizing of independence and the assumptions that individuals who rely on any kind of assistance are deficient (Teghtsoonian, 2009). Specifically, in a mental health context the legislation, research, and social services are aimed at providing relief for informal carers. This suggests that individuals in contact with the mental health care system - who due to deinstitutionalization are faced with insufficient public support in the community - do not have enough insight or capacity to self-regulate their illness. The individuals or "young carers" who provide their dependent parent with care, are seen as responsible, moral citizens who need to be relieved of making decisions for their family members' well being (Henderson & Forbat, 2002). This construction of the "carer-dependent" relationship is often contested in the literature as dependence is seen not as a negative state, but as an inherent part of the human condition (Kittay, 1999). If dependency were not seen as an exceptional and socially undesirable circumstance, but instead as a common and inevitable human experience, supports provided by governments would logically have to increase.

The construction of a "carer-dependent" relationship makes it difficult for both the carer and the "dependent" individual to see themselves in any other way, as many individuals internalize their respective discourses of carer or "dependent". In addition, it ignores the possibility of reciprocity in caring relationships (Keith & Morris, 1995). This statement is not made to minimize the challenges that informal carers face, but there is often a positive effect of providing support that is erased and lost in the "burden

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discourse". When research solely focuses on the "burden" aspect of caring, it is not acknowledged that individuals do not always see themselves as "caregivers" or they do not understand their relationship with the family member solely in terms of the care they provide (Kittay, 1999). When someone is named a "caregiver", they are positioned in a way that discursively narrows their construction and possibilities. In line with this critique, the phrase "young carer" is presented in quotations throughout this thesis, in order to leave open the question of whether young people think of themselves as carers before they came into contact with researchers and professionals (Keith & Morris, 1995; Smyth et al. 2011).

The Westernized Childhood

In terms of informal care, most people agree that dependence may not be a unique circumstance, but a debate starts when individuals consider whether a young person should be providing care for their parent. Over the past century there have been many changes in expectations of young people in Western or "developed" countries (Olsen, 1996). Childhood is idealized as innocent time that is free of work and responsibility, and there is also a sense that children are vulnerable and passive recipients of their surroundings. Accordingly, the idea that a young person should have a carefree childhood that is protected by their parents and the government is persistent in Western societies (O'Dell, Crafter, de Abreu & Cline, 2010; Gladstone et al. 2006). However, this standard was developed among white, upper-middle class individuals, and set the ideal for all children regardless of their family's level of income or their cultural values. A

responsibility-free life is not the reality for many children, especially those who come from families of lower socio-economic status. It is therefore difficult, or even unreasonable to articulate a clear standard of what is a "normal" childhood based on an individual's age and responsibility level (Lloyd, 2006). Despite this complexity, "young carer" literature often makes the assumption that individuals providing a certain level of care are missing out on this "standard" or "normal" childhood. When it comes time to look into *how it is* that these children become carers, the ideas regarding the neo-liberal "carer-dependent" relationship kick in, and the young person becomes inevitably burdened looking after someone who is incapable (Olsen, 1996).

These dynamics and discourses are especially significant when it is a parent who is in contact with the mental health care system and it is their child providing care for them. This caring relationship may prompt concerns regarding the young person's rights and welfare, and as a result professionals may incorrectly associate a "young carer" as someone who always needs protection (Benjet, Azar, & Kuersten-Hogan, 2003; Stanley et al. 2003). The parent tends to be seen as unable to provide their child with a "normal" childhood, thus there is an increased assumption that they will have inadequate parenting skills. As a result, research has produced many parent education programs to "teach" parenting skills to individuals who are perceived not to have them (Benjet et al. 2004; Edwards, 1995). When an individual has a mental health issue their parental capacity is measured against society's idea of an optimal family - an image already unattainable for individuals who are not white, married, or wealthy.

Lack of Large Sociopolitical Considerations and Small Contextual Factors

The final element of critique of the literature on "young carers" suggests that research has tended to ignore the small contextual factors that make each caring relationship unique, and at the same time the research lacks the critical analysis that draws attention to the larger picture. It is suggested that young people come into a caring role due to needs for informal care that are not met by other adult family members and the available supports in the community (Becker, 2007).

Questioning how it is that the state and other adults do not take up the caring responsibility - leaving it with a young person - has not often been the part of the traditional research scope. This has meant that the developed supports and legislation do not question the existence of young carers. Instead, although they have good intentions to help young people in need, they speak of young people who care as if their contributions are an inevitable part of society (Lloyd, 2006). The larger picture here might direct attention to the structure of the mental health care system and its shortcomings if young people have to provide the care to sustain it. In the UK, campaigning for the rights of "young carers" has been a successful social movement that has resulted in "young carers" being included in policy and legislation (Becker, 2007). An example of what this looks like on the ground level is an after school program designed for individuals who identify as "young carers" to lessen their social isolation (Becker, 2007). This may be a positive solution for the short term, and is not the focus of this critique. The problem is that these programs and the supporting research are not designed to stop these young people from

caring, but rather to sustain their caring, ensure that the informal caring system doesn't break down, and protect the public care services from additional demands. (Lloyd, 2006).

Eva Kittay (1999) uses the term "dependency work" to describe the provision of informal care, and suggests that while this work exists it is contributing to the inequality faced by women. In dominant political discourse, dependency work is not seen as an activity that contributes to the economy, and it does not allow the individual providing it to compete for social goods. Although women are being provided with the same educational opportunities as men (and in many cases outnumber them in University classrooms) they are still overwhelmingly the majority of informal caregivers. This role confines women once again in a domestic setting, and unless support is increased in the community, this will continue (Kittay, 1999). "Young carers" on the other hand have been found in some small studies to be made up of roughly an equal amount of males and females. Despite these finding, gender, and other significant factors like age and socioeconomic status are not taken up in the research; as if caring relationships exist in a social and political vacuum.

2.0 METHODOLOGY

The theoretical approach underlying my research integrates elements of critical social science theory, feminist theory, and postmodernism. Critical Social Science theory suggests that research should provide a critique of the traditional approaches and taken for granted dominant discourses. This should be done in order to illuminate the material conditions that structure a particular phenomenon or problem, and suggest a plan to change the conditions that sustain it (Kreuger & Neuman, 2006). My positioning in critical social science is also influenced by critical feminist theory as it places an emphasis on giving voice to the individual's lived experience (Gringeri, Wahab & Anderson-Nathe, 2010). Using the process of reflexivity to analyze the power of the researcher in the research relationship is also a commitment that I have gained from feminist thought. Finally, postmodernism offers yet another lens to inquiry by focusing on the deconstruction of critical theories in terms of power, the nature of change, and the nature of the individual (Capper, 1998). Postmodernism shifts from the search for a general meta-narrative "truth" towards the explorations of the uniqueness in the form of stories, wisdom, myths, and legends. The postmodern feminism that I draw on moves beyond the sole focus on women's issues to seeking to eliminate all hierarchies of knowledge construction (Gringeri et al., 2010).

These intertwined perspectives inform my critique of the traditional explorations of the topic "young carers" and orient me to questioning whose interests are served or ill-served by dominant approaches to knowledge building in this area. I believe that current research studies about young people who provide care have not captured the full range of

possible lived experiences of the individuals involved and often ignore contextual factors. This focus of the research on the young people themselves ignores a lot of "why" questions and instead places a lot of responsibility on the individual receiving support.

In this study I used a combination of methodological approaches. Part of my methodology will address my interest in hearing the voices and lived experiences of people who, when young, provided a significant level of care for a parent in contact with the mental health care system. Drawing on a narrative approach to generate individual's stories as "data sources" aligns well with my theoretical perspective, especially feminist postmodernism, that posits that knowledge is "best created" by first person accounts (Carter & Little, 2007; Clandinin, 2006).

The other methodology used was the broad framework of institutional ethnography which complemented the narrative approach by challenging the taken for granted assumptions present in the "young carer" discourse (Carter & Little, 2007; Mason, 2002). Institutional ethnography is informed by feminist research that challenges and critiques a traditional approach to "ways of knowing" (Neysmith, 1995). Unlike a narrative approach, institutional ethnography is focused on discovering how social processes come to be organized: it attempts to uncover the invisible forces or "ruling relations" that organize the local settings of everyday life (Campbell & Gregor, 2002). Specifically in terms of my research project I was looking for the "ruling relations" underpinning the dominant views of the dependent-carer relationship, a Western idealized childhood, and the lack of focus on structural issues in mental health (Devault & McCoy, 2003).

Drawing from these theoretical and epistemological frameworks, I undertook a small qualitative study of young people who had cared for a parent in contact with the mental health care system. In line with a critical social science theoretical orientation, I felt the most effective way to generate data was by speaking with individual people to hear their voice and tell their stories. A critical social science lens suggests that human beings have the potential to be creative, adaptable, and are trapped by different intersecting oppressions (Kreuger & Neuman, 2006).

2.1 Sample

I sought a purposive sample of "young carers" who satisfied two criteria: 1) Had a parent who has been in contact with the mental health care system for a significant period of time; and 2) Had provided a significant level of care for that parent during a period of time when they were under the age of 17. In addition I sought participants who were no longer young (who were over the age of 18), and were no longer providing a primary level of care for their parent. This point of view has been rarely tapped in "young carer" studies and has the promise of enhancing understanding of how people reflect on their care giving experiences with the benefit of time and hindsight.

To locate a sample I recruited initially from the population of McMaster University students. The student population at McMaster University is made up of approximately 26,000 students, 55% female students, 15% international students, and 13% part-time students (McMaster University Fact Book, 2008-2009).   At the end of March 2011, after receiving ethics approval, I posted several recruitment posters

(Appendix B) throughout McMaster's Campus. In addition, in four large sociology classes, I presented my research project, and asked interested individuals to contact me by e-mail. Over a four-month period, eight interested individuals contacted me, and I conducted interviews with four that met study the criteria.

The four sample members were all women and ranged in age from 22 to 35 (See Table 3.1). All were Caucasian, English speaking residents of Canada, who indicated their family was middle-upper class. Two of them were undergraduate students at the time of the interviews, one had just graduated University, and one was working in the mental health field with a Masters Degree. All of the women indicated that they had provided care as a young person for their mothers who were in contact with the mental health care system with illnesses ranging in type and severity. All stated that when they were providing care for their mother, another parent (in all cases a father) who was not in contact with the mental health care system, lived in their household. Each woman also had siblings ranging in number from one to three who lived in their household during the time they provided care. All of the women indicated that they no longer live with their mothers but still play a role in their support.

This sample is homogenous in respect to gender, race, and socioeconomic status despite my initial hope to recruit a more diverse group. This homogeneity means, of course, that the transferability of these women's experiences to "young carers" in more varied social locations must be qualified (Mason, 2002). However, their relative homogeneity does offer a valuable window into understanding how a relatively privileged

subset of the wider "young carer" population experience their caring roles and social contexts.

2.2 Data Collection

Study participants took part in semi-structured interviews with me between April 2011 and June 2011. I used qualitative interviews as my data generation strategy because my theoretical position indicates that the most legitimate way to gather information is by actively talking with individuals and drawing forward their views, thoughts, and opinions (Mason, 2002; Riessman, 2004). Feminist theory suggests that no researcher can be neutral, removed, or objective, and instead both the researcher and the participant are co-creators of knowledge that is completely dependent on the context of the interviewing situation (Neysmith, 1995). As I listened and responded in the interviews, I tried to constantly reflect on this principle.

The interviews took place in mutually agreed upon locations that ensured privacy and confidentiality. I asked the participants to read a Letter of Information (Appendix C) and sign an informed consent (Appendix D) before participating in the interview. The interviews were semi-structured and followed an interview guide (Appendix A). At the beginning of interviews, I was very transparent in telling each participant why I was interested in the topic of "young carers", and the fact that I experienced providing care for a parent with a mental health issue when I was young. I also explained that I chose interviewing as a methodology because I believe that knowledge is best created by first person accounts (Clandinin, 2006; Neysmith, 2005).

Lasting approximately 60 minutes, the interviews flowed in a conversation format; the questions were not asked in order, but eventually all pertinent subjects were covered (Ristock, 2002). I asked participants to share their stories of caring for a parent with a mental illness, and to amplify and illustrate this larger story with specific memories, incidents, or situations to further clarify the experience (Riessman, 2004). This approach is rooted in a postmodern conceptual lens that uses the unique and textured aspects of individuals' lives to understand social reality (Clandinin, 2006). In order to build on conceptual insights from institutional ethnography, I framed questions concerned with the discourses and institutional processes that shaped the individuals' everyday lives. While drawing forward a narrative or story, I used the participants' words or phrases as entryways into understanding how their stories were organized by larger structural and systemic forces (DeVault & McCoy, 2002). With the participants' written permission, the interviews were audio-recorded and I took notes as we spoke.

To ensure the validity of my findings I invited each of the women to participate in a follow-up interview, and two women agreed to meet. In these interviews the women and I discussed the themes I had identified in the findings. This allowed me to check the trustworthiness of the data and my interpretation (Capper, 1998; Foster, 2009).

2.3 Locating Myself in the Research

Being an individual who herself identifies as having been a "young carer", presents the particular methodological strengths & tensions of the insider role in research (Foster, 2009; LaSala, 2003). Like LaSala (2003), I reject the idea that there can be a

rigid objective "subject-researcher" relationship in qualitative research, an analysis supported by literature that suggests at all times an individual is both an insider and outsider in research depending on their personal characteristics alone such as gender, class, race, ability, and sexual identity (Green et al. 2009). This highlights the important point that no matter how much of an insider I may have felt at times, I had different experiences than the individuals I spoke with, making me very much an outsider (Kanuha, 2000; LaSala, 2003).

Before engaging in interviews, I researched common bias "traps" in insider research, and this allowed me to be very aware when these issue came up in interviewing. If a participant described something about caring, and I assumed I knew what they meant from my insider experience, I asked them to further clarify. I also often felt that my insider knowledge on the subject enabled me to ask questions about a particular subject that other individuals might have not seen as significant (LaSala, 2003). My attention to my insider positioning was particularly significant as I analyzed the interview data and is taken up below.

2.4 Data Analysis

I transcribed the audio taped interviews, and began the data analysis following a process used by Ristock (2002) in her research on violence in lesbian relationships. In her work, she uses a postmodern feminist lens to disrupt taken for granted assumptions while placing the lived experience of the individual at the center of the research (Ristock, 2002). This approach complemented the use of institutional ethnographic and narrative

methods in the data collection stage, as it helps to illuminate both the "story" and the "ruling relations" (Campbell & Gregor, 2002; Clandinin, 2006)

Ristock's (2002) method of data analysis consists of three separate readings of the transcript, each time looking for different elements in the data. The first pass through the data is concerned with looking for the material content of the story, or what the individual is trying to say. I transcribed and analyzed each interview's content immediately after it had taken place, thus was also able to adjust the wording of subsequent interview questions and pinpoint areas in which I might seek more detail. I read each transcript several times, and then went through each transcript line by line placing together on a separate document the quotes that told a similar story. I then named each cluster of quotes, which provided a list of themes that came up in each interview. As I included new interviews into the data I revised and adjusted the themes. I then went back to my two research questions and explored how they related to them. I organized the themes in a way that best represented the overall story of caring giving as a young person (Riessman, 2004).

Continuing with Ristock's (2002) data analysis method, I read through each transcript again keeping in mind that the stories the women told represented how the events were experienced at the time and how they are now remembered and how they are expressed. To analyze the discursive content I used an institutional ethnographic approach to listen for how the women's understanding was structured now that they are adults. I explored what type of language was available to women to speak about being a "young carer" or being in an "informal caring relationship" to consider what kind of

vocabulary was available to them. Dominant language operates to exclude experience that has no vocabulary - or a less established vocabulary - of its own (Ristock, 2002). I found that there were very few words or phrases of "dominant language" with which participants spoke about caring relationships. There did not appear to be an available vocabulary about "young carers" like there is now about the topic "violence against women", for example. In the discourse of violence against women, people use dominant words like: perpetrator, victim, or emotional abuse, among others to describe their experiences or to talk about the topic (Ristock, 2002). The lack of discourse available made it difficult for me to gauge whether or not the women in this study subscribed to the norms when talking about their experiences. This being so, I listened instead to the tone and pace with which women spoke. I noticed in some areas the women were eager to answer the questions, so much that they cut me off from speaking. I also noted where the women, who were quick to answer, slowed in their speaking and began to think out loud.

Finally, Ristock's (2002) third type of "reflexive" data analysis, was extremely important due to my location within the research. I located myself as a white, able-bodied female, who as a young person experienced providing care to a parent with a mental health issue. My consciousness of my insider position was discussed above, and played a large role in the analysis of the data. I made notes when I felt like a particular experience resonated with me, or when one surprised me (Brannick & Coghlan, 2007). I engaged in a reflexive process where I could explore my insider bias, and examine how my presence influenced the interview (Foster, 2009). Reflexivity allowed me to explore

my social identity and values, and reflect on how it may have effected the data interpretation.

3.0 FINDINGS

The findings of this study illuminate how the participants, who are now adults, remember their lived experiences as young people providing care. This section begins with a description of who the participants were, and how they found themselves to be in a caring role, what their caring roles consisted of and why they continued in them despite other options. In addition, contextual factors are explored to help answer why is it that these young people were caring. In the second part of the findings I used Devault's approach (2002) to listening to interviews to discern "ruling relations", with an eye to the structural forces that shaped their pathways as carers and their reflections on those pathways. Two major themes were found in all the participants' stories: the privatization involved in care giving and how the women - now adults - understand the structure and meaning of their caring role as a young person.

3.1 Participants' Accounts of their Caring Role

This small sample corresponded demographically with some patterns in other studies in this area: the "young carers" were female, and the "dependent parents" were mothers. However, it differed dramatically in that the degree of social isolation identified in much "young carer" research was not present. All participants had siblings living in their house, and there was another parent (a father in all cases) present who was not in the contact with the mental health care system. In some cases, extended family members were aware of the mental health issue and difficulties present. The particularity of this

sample therefore can contribute usefully to the broader literature, illuminating the experience of a distinctive subset of young carers.

Young Carers in Context

The caring activities that the women engaged in aligned closely with other studies, which suggest that children of a parent in contact with the mental health care system primarily provide "emotional care":

> *We we're definitely like "therapist" kids. Mom would spill everything to us and kind of expect us to, I guess be there to bounce ideas back off, but we were much too young to understand what was going on so we just listened.* [1]

> *If she [mother] was like crying or whatever I would sit on the couch with her and provide comfort to her and just let her, let her cry or let her rant… just offer my presence more than anything.* [2]

Another participant indicated that her emotional role was more active than just listening:

> *Mostly it was pacifying her [mother]… bring her down from hysteria and bringing her back from the ledge, um… re-orienting her to reality, and kind of acting as a buffer between her and other members of her family.* [4]

The women did indicate that at times they had other more practical responsibilities:

> *I had to shower myself, by myself, wash my hair by myself without my mom's help.* *[1]*

> *I would do simple things like just take care of the house, chores and house work, and things like that, go and get the groceries and anything she needed. [4]*

It appeared, however, that the practical caring responsibilities were minor in comparison with the amount of emotional caregiving provided by these women.

Appreciating the participants' unique stories and surprising similarities is the key to understanding the care they provided (See Table 3.1 for Summary). The first participant lived with her younger sister, her father, and provided care for her mother. Although she had suspected that her mother was experiencing difficulties as she grew up, this woman never knew until she was an adult that her mother was formally diagnosed with depression, or that the care she was providing for her mother might be considered to be unusual. Her mother's mental illness and the care she provided was kept a secret from her extended family and friends for most of her life. The second participant lived with her twin sister, one older sister, one older brother, her father, and provided care for her mother. This woman's mother was diagnosed with bi-polar disorder shortly after she was born, and she indicated that she provided care for her mother because she felt it was her fault that her mother was ill. Her mother was in recovery at the time of the interview. The third participant lived with one younger sister, one young brother, her father, and provided care for her mother. At the time she had two older sisters who did not live in their household. Her mother was diagnosed with borderline personality disorder, relatively late in life. She provided care for her mother from her late teens and continued to provide this care when she had moved out of the house. The fourth participant lived with a younger brother, her father, and provided care to her mother. At the time she had three older sisters who did not live in their household. She began caring for her mother in her early teens, when she was entering high school. She felt that her mother

showed signs of depression throughout her childhood, but her behavior escalated, and she

was finally diagnosed with borderline personality disorder.

Table 3.1 Summaries of Participants' Contexts.

4	Female	Early Twenties	Mother	Borderline Personality Disorder	Married living in same house	1 younger brother 3 older sisters	Beginning in late childhood	Yes	Some

	1	2	3
Participant Gender	Female	Female	Female
Participant's Age	Early Twenties	Mid Twenties	Early Thirties
Care Provided To	Mother	Mother	Mother
Parental Mental Illness Diagnosis	Depression	Bi-Polar Disorder	Borderline Personality Disorder
Parental Status	Married living in same house	Married living in same house	Married living in same house
Description of Siblings	1 younger sister	1 twin sister 1 older sisters 1 older brother	1 younger sister 1 younger brother 2 older sisters
Primary Carer	Always	Always	Beginning in late teens
Extended Family Awareness	Yes	Yes	Yes
Extended Family Support	No	Some	No

In all cases, and unlike a good deal of the samples studied in the "young carer" literature, the women in this study indicated that their families did not experience many financial problems:

We certainly weren't wealthy but we never lacked anything. I think that was protective in a way for our mother because she never had to worry about working or having those additional stressors. [2]

"[We're] definitely a middle, upper-class family, so no issues in that way." [3]

In three of the cases the family was sufficiently well off financially that their mother did not need to be employed.

Entering and Continuing in A Caring Role

Asked how they came to assume so significant a role in caring for their mothers, some participants described it as a natural response to their circumstances:

> *In the beginning I wanted to help her and I was very sympathetic and I was worried about her, that the medical issues that she was talking about were real and were life threatening. So I took on any caring and supportive roles, I took that on willingly and I had no problems doing it.* [4]

The literature suggests that most young people become carers due to a lack of options, due to the unavailability of other people to support their parents. Some of the women indicated that they had been caring for their mother since they could remember, but others began their caring role later in their youth. What was it about these particular women that made them the primary carer out of all of the other people in their families? As I invited the participants to talk and reflect about their experiences, a mix of pressures, forces and obligations emerged as factors that influenced them in becoming carers.

In the interview I asked specifically how it was that they became the primary care giver for their mothers, even though other potential carers were available. The women did not provide quick reflex responses to this question, and it appeared as if it was the first time they had thought about it and were reasoning out loud:

> *At some point everyone just assumed that I would continue to provide support and care… And we just kind of settled into roles, who knows how it actually happens you just get comfortable with the fact that this is how our family functions.* [2]

I think it was because for some reason she [mother] demonized my father... So I think in that regard she didn't turn to him, she didn't ask him for support, and I was the oldest child, I was in her eyes an adult... and I was there. [3]

It just kind of happened just cause no one else was there, I mean my dad um... works a lot and my brother was too young and my sisters didn't live at home, so then there was kind of me. And me and my mom were really close when I was growing up you know, she was my best friend, and yeah so we were super close. [4]

The first woman quoted above as [2], appears to have become a carer as a result of incremental, unnoticed decisions. In the interview it was later revealed that she took the initiative to be her mother's carer, as she felt responsible for her mother's illness. The second participant [3] indicated that she felt an obligation as the oldest child to take over a role that her father could not fulfill, because he did not have a good relationship with her mother. The third women's quote [4], suggests that there may have been some coercion into her caring role, because she was "close" with the mother, and she was the only one at home, besides her brother who was "too young". All women indicated that their fathers were working long hours, and this may have contributed to their significant caring responsibilities. In order to understand these generally tacit decisions and divisions of caring responsibilities, I asked participants to expand, if possible, on how they came to care.

Social Isolation within a Social Network

Many "young carer" studies have found that a main reason a young person assumes the caring role is because they don't have a choice - no one else lives with them and their parent needs support. This was not the case for the women in this study: they

indicated that in addition to the family members in their households, they had friends and

other informal and family networks:

> *I was very close with my friends and we were very open about our relationships with our families.* [3]

Some of the participants noted:

> *I had a few friends I would talk to, but I would never give details.* [1]

> *My friends never understood. They knew my mom from growing up and they'd be at my house all of the time. In high school they'd come over everyday after school, so they knew her, but they didn't see it, so they never really understood what I was dealing with. When I would come to them, upset or needing help or anything, they didn't, they couldn't understand.* [4]

The women felt that although they were in constant contact with people, they were

isolated in a different way because no one understood exactly what they were going

through.

The women in this study also made reference to their fathers, and explained why

they thought they played less of a primary caring role for their mothers:

> *My dad was never home and in the mornings, he's in the music industry so he works at night, and sleeps during the day…I know that dealing with my dad was a huge stressor for her [mother].* [1]

> *I can't hold it against him [father] I guess, but it probably would have been more appropriate for him to actually provide more care and encourage her more to get treatment and/or forced her to get treated. But he never really did, so we all just had to maintain.* [2]

> *There wasn't a lot of dialogue between me and my dad about it. I just kind of tried to do what I did and because I didn't want to bother him with my problems with it because I knew he was doing the best he could.* [4]

It seemed that participants took on caring roles instead of their fathers for a number of reasons. A major reason was the fact that the fathers were working a lot, but other factors were revealed such as the fact that some of their fathers had poor relationships with their mothers. Interestingly, some participants expressed a large amount of sympathy for their fathers, and it appeared that they felt responsible to protect them from the caring role. None of them indicated that they felt resentful towards their father, and one woman indicated that the sole reason she continued to care for her mother was for her father's well being:

> *He feels an overwhelming sense of responsibility as her husband to support her, he said, "If she had something like MS or Cancer or Alzheimer's I wouldn't leave her." So his view is, "I'm her spouse; I need to support her regardless."… And I feel like he needs all the help he can get.* [3]

In follow-up interviews, I shared these finding with participants and inquired into why they felt they could have dealt with the caring role better than their father. One woman indicated that she thought women in general have emotional intelligence as an innate ability, therefore are better able to care. Another women was surprised with the findings and indicated that at the time, she did not consciously try to protect her father from caring responsibilities.

When the women explained why they provided care instead of their father, I found myself wondering where extended family and friends were during this time. In the interviews I also asked the women how their extended families supported them. One felt very well supported by her extended family and church, but this support did not appear to affect her caring role:

I think that having the support from her [mother's] parents who live like a block away from us was important, and we lived in a nice area. We were part of a very wonderful church and all of those things are very beneficial in allowing her to be as high functioning as she was. [2]

In contrast, another participant felt she had no support from extended family members.

The other two participants fell somewhere in the middle:

We really shut the world off and the extended family off for years, but when she attempted suicide she was with her sister and then you know it was kind of chaos and we kind of had to start telling people. And it I don't think it came a huge shock to them that there was a serious illness going on, but it's not something that we had ever had dialogue with them about. [3]

My one Aunt wanted me to come live with her. Basically all of them wanted me to leave the house, to not live with her [mother]. That was the only solution that they gave. [4]

Neither participant commented as to whether this extended family involvement was helpful; it seem sporadic rather than ongoing. Despite the women in this study being in the presence of friends, a parent not in contact with the mental health care system, and sometimes extended family members, they still took on the primary caregiving role for their mothers. The participants also felt isolated themselves, and found that they were not well understood among their social network.

Participants' accounts revealed complex gender dynamics at play. One woman noted explicitly that being female had contributed to her becoming a carer:

I think that she [mother] sees the females as the caregivers and the males as… it's a different role, as a bread winner almost, but no responsibility for caregiving. [3]

Although there were no male participants in this study, larger studies indicate that "young carers" as a group are different from all other types of informal care groups because they are comprised of roughly the same amount of females as males (Aldridge, 2006). Interestingly, the overwhelming majority of individuals being cared for by young people are female. This may occur because if a male needed care, he is more likely to have a spouse to provide care for him (Grant el al. 2008). In this study, some of the women felt sympathy for their fathers, and that contributed to their assumption of caring responsibilities. This makes me wonder if there is a comparable degree of sympathy for mothers who assume caring roles. The history of women's involvement in dependency work suggests otherwise - that there is no sympathy for a female carer, as it is a "natural" role for them (Kittay, 1999).

For this particular group of financially privileged women, their socioeconomic status did not influence them in becoming carers. The women were not socially isolated, but it seemed that they were strongly influenced by the desire to protect their fathers from caregiving responsibilities. The influence of gender in assuming a caring role did not initially appear as a strong theme, but it has shown up more implicitly in the relationships these women had with their fathers.

This section of the results reveals the lived experiences of women who provided care for mothers in contact with the mental health care system. This lived experience is broken down in order to understand the process involved in the women actually becoming the primary caregiver despite having another parent present who was not in contact with the mental health care system. The influencing factors of social isolation and gender

provide insight into the incredible variability and uniqueness of each woman's experience.

3.2 Looking Back on Being a "Young Carer": Its Social Structuring and Meaning

A distinctive aspect of this study was the fact the "young carers" interviewed, were no longer young, and no longer provided a primary level of care for their parent. Instead they were adults, and had time to reflect on their care giving experiences and how they affected their lives. Following Ristock's approach to multiple readings of transcripts and Devault's approach to listening to interviews to discern "ruling relations", I examined and re-examined participants' stories and how they told them with an eye to the structural forces that shaped their pathways as carers and their reflections on those pathways (Devault, 2003; Ristock, 2002). Two themes were discernible in those pathways: (1) the privatization and the silence surrounding caring; and (2) how the women, now adults, understand their roles as young people providing care, and how that has shaped their identities.

The Privatization of Informal Care

The women's roles as carers were hidden for two inter-related reasons: they did not want to attract the attention of professional individuals who may assume they needed protection; and they were protecting the secret of their mother's mental illness- a diagnosis that brings shame and stigma. Several spoke about the importance of their families appearing "normal" to the public and therefore, they sought to keep their mothers' mental illness and their roles a secret because of their loyalty to their families.

Obscuring Caring

To some of the women, it was quite clear that they should not talk about their mothers' mental health issues or their caring roles:

I remember them [dad] saying, "you can't be telling people that." [1]

Others kept their mothers' mental health issues a secret because they did not know that their lives were out of the ordinary:

I didn't know how much they [extended family] knew what was going on until I was older as well, because I never knew there was a problem.[4]

They received indirect messages from family members that their roles and their mothers' illness was undesirable:

I don't know that anybody knew how much care I provided to my mother. I don't even know if my siblings or my dad knew like that I was supportive of my mother in that way. I never made a big show of it. [2]

At family functions on my dad's side, my mom usually won't come. So everyone is asking, "Where's your mom, what's going on". We just have to cover with, "she's just not feeling well" or "she has a stomach bug." [4]

These quotes suggest that the participants went through a great deal of effort to appear "normal" to outsiders. Nothing about the women's lives could give away their secret.

Family Loyalty

In addition to appearing "normal" in order to keep their mothers' mental health issues a secret, participants also spoke with a very strong sense of loyalty to their mothers. Often, describing a challenging aspect of the care they provided, they would immediately provide a modifier, or phase to assure me that despite the difficulty they still loved their mothers:

> *I guess there was a level unpredictability in our family but um I mean my mom, she was the best mom that she could be, given her limitations.* [2]

> *Sometimes when I talk about it to some people, it seems like I don't love my mom or that I don't care, and that's not it at all.* [4]

In addition, some of the women spoke openly about the hard time that they had talking about their mothers' mental health issues to other people:

> *I shouldn't be talking about my parents' issues, I shouldn't be talking about them when they're not here, they have their own issues they can deal with them.* [1]

> *I didn't [talk about mother's illness], part of that it was that I didn't want to demonize my mom, I didn't want to talk bad about her.* [3]

Whether the women received direct or indirect messages, there was a clear sense that mental health issues, and their role of caring was to be kept from other people.

In this study- where the individual providing support was the child and the person requiring support was the parent- many factors complicate loyalty. Some of the women noted that their mothers understood and appreciated the support they were receiving, but felt bad about it, for example:

She [mother] was appreciative of the support I think she, she feels badly that I felt I had to take on that role because that was not the dream my mother had her dream was to mother her children not have her child mother her. [2]

I think the fact that she [mother] saw my sister and I were taking on all of these responsibilities that we shouldn't… I think that bothered her because it made her feel inadequate. [2]

The factor that appeared to have largest impact on the caring relationship between the parent and child was the severity and type of mental illness that the mother was experiencing. When the severity of the mental health issue was mild, or the mother was in a recovery stage (at the time of the interview), the women spoke of a more positive caring relationship, and seemed to accept their roles without a hint of resentment. This also influenced the women's degree of respect for their mothers as parents:

I have no regrets, I wouldn't change my life… I mean yeah, I guess it would have been nice if I didn't have to have all of those responsibilities as a young kid, but I guess I'm glad that I had that opportunity to provide care to my mother and the fact that she now is so well, makes it all worth while. [2]

I totally respected her authority. [2]

In contrast, when the severity of the illness was moderate or severe, as in the cases when the mother was diagnosed with borderline personality disorder, the women described challenging relationships with their mothers:

I feel guilty, very, very guilty I mean I can't confide in her [mother]. I can't talk to her about meaningful things in my life because I know whatever her response is I'm not going to consider it anyway. [3]

> *You can't live in her [mother] world it doesn't make sense, um… it's just crazy but she expects you to follow her rules and she wants you to see the world the way she sees it.* [4]

Providing care when the mother's mental illness was more severe definitely put strain on the relationship:

> *I don't want to be her parent, and I don't want to be her friend.* [3]

> *It's not nice… it's awful. You don't want that with your mother, I never thought it was going to be like that, but you just do what you can. I still do see her and when I do I try to be very positive and just try to be okay, and we just take her how she comes. And I don't see our relationship getting better as time goes on, we'll probably grow further and further apart.* [4]

Another factor influencing the caring relationship appeared to be the timing in participants' lives of their mothers' first mental health symptoms. When mothers had experienced a mental health issue for the participants' entire lives, they were more accepting of their caring roles:

> *Growing up that's what I thought all kids did, I thought it's just what you did for your parents. They take care of you so when they need you, you take care of them.* [1]

> *I just accepted the fact that my mom was crazy and I was okay with it. And I knew that were not like any other family, and that was okay.* [2]

When the mothers' mental health issues occurred later in participants' youth the women appeared to experience more difficulty in their roles as carers for a mother who previously cared for them:

> *I didn't get a chance to say goodbye really, you just kind of accept that the mom you had isn't there and um… yeah so that's something that I still deal with and I try not to think about it, and I try not to let it get to me, because it does upset me.* [4]

I was struck that the women with mothers who experienced less severe mental health issues, would talk about their care giving experience in a noticeably upbeat tone that didn't match the subject they were describing. This upbeat tone was not maintained throughout the entire interview, suggesting some mixed feelings or ambivalence about their experiences:

> *I usually don't cry when I talk about my mom, but it's good, cause you always think that you've arrived, you always think that you've dealt with everything, you're good you don't need to revisit this anymore, but apparently there is still parts of me that still needs, I guess to grieve.* [2]

The women whose mothers were experiencing more severe mental health issues, spoke in a tone suggesting they were upset and were completely upfront about that fact. The ways in which these participants' experiences and activities as young carers were required to remain hidden, ensured then, that they were contained in the private sphere. Their reflections on this privatization process linked both with the stigma associated with mental illness and with the shortcomings of public services as they witnessed them.

Mental Illness & Social Discrimination

Asked how they thought about public supports for people with mental health issues, the women in this study all indicated that society in general was responsible for supporting individuals with mental health issues with the end goal of recovery and a high quality of life. They varied in how well they thought society was doing, variability that tied closely to the amount of formal support that their mothers received. With the

exception of the woman whose mother was in recovery at the time of the interview, the

others did not feel that they had received an adequate amount of formal support:

Informally she's always had a lot of support. Formally it's crappy, just really crappy. Just the fact that she was only diagnosed at 58 years old is ridiculous; it wasn't like she didn't have some interface with the mental health system! She was just medicated, medicated, medicated and it gave us nothing to focus on, it gave her nothing to focus on. Like she knew something was wrong and didn't know what it was, it wasn't like she didn't try to get help. She was referred to the mood disorders clinic a few years ago, and the psychiatrist at the clinic, saw her once, gave her some offhanded diagnosis, and said hire a psychologist privately... and that was it. [3]

I feel horribly let down with the system and just so frustrated, and I just feel, for the families, I don't know what else we could have done. [4]

At the same time, some of the women also indicated that they felt their mothers

had a large degree of personal responsibility for their illness and recovery:

She needed to learn skills such that she was in control of her illness and it didn't control her. And it took a long time to learn those skills and to practice them enough and believe that she could use them and be well. [2]

You really have to work to get better, you have to want to get better. So from that, like it's just, I don't know how hard she's working, how bad does she really want it. [4]

Within their accounts then, there was some uncertainty about whether mental health is a

public or private issue; they seemed torn between society being responsible and their

mother being responsible. However, one participant was exceptionally definite in

identifying mental health as a public health issue, and highlighted the problem of

individualizing it and individual responsibility for addressing it:

We want all of these individual problems to be individual, we don't want them to be a social issue. But they are social issues, and... if other people don't know about it, then it's a personal issue, and then the person has to deal with it. It

> *doesn't have to be that the community structure has to change to help these individuals.* [1]

This woman indicated how in our society mental health issues are seen as personal issues, thus encouraging the person to change, not the system. Her commentary resonates very closely with analyzes of neoliberal trends toward the privatization of problems once understood as matters of public concern and responsibility (Teghtsoonian, 2009).

The informal care that these women provided as young people was hidden in order to keep their role and their mothers' illnesses a secret. This need for secrecy was deepened by the loyalty the women had to their families- especially their mothers. Loyalty and the relationship between mother and daughter were influenced by the severity of the mothers' mental illnesses. The women's view of the formal mental health care system in Ontario was closely tied to the amount of formal support their mother received. Some did not feel that their mothers received adequate formal support, but were unsure if society or their mothers were to blame. The lack of formal support for the mothers of those studied here suggests that privatizing mental health care and silencing the individuals in contact with it, operate to relieve demands on public mental health services.

"Young Carers" Looking Back from Adulthood: Discourse Tension

As noted earlier in introducing this study, one of my interests was in examining the imagery of "young carers" that has emerged in research and services discourses in the United Kingdom and elsewhere. In the interviews and analysis of the transcripts, I was

therefore especially interested in exploring how participants took up or experienced some prominent themes present in the literature, notably: the lost childhood and the burden of care. For this group of women it appeared being young in age added to privatization of care due to a lack of resources, while a privileged socioeconomic status allowed them to experience a "normal" Westernized version of childhood. For the most part, the women in this study did not identify with the "young carer" discourse raising interesting questions about the usefulness, for them at least, of the practical recommendations that have flowed from it.

"Lost Childhood"

Some studies of "young carers" have suggested that children's rights have been violated by their caring role (Aldridge & Becker, 1993). The women in this study did not indicate any hint of such "lost childhoods". It seems likely that the socioeconomic status of their families lessened that possibility. They were all from relatively financially privileged circumstances and thus were able to participate in extra curricular activities and other events characteristic of the Westernized version of childhood. Young people who provide care and do not come from wealthy families, (a common characteristic of those studied in the "young carer" literature") would seem more likely to "lose" childhoods in material terms. That said, the women studied here did- with hindsight, and some hesitation- identify some emotional losses.

Only one woman in this study indicated that her age played a major role in influencing why she became a carer, because she was the oldest child. Some of the

participants described how being a young person during the time they provided care affected their life:

> *I mean I'm a little kid right, I don't know, I can't label guilt, and can't label the fact that I felt responsible for my mom.* [2]

> *When you're in your late teens and early 20's your still learning and growing and finding out who you are and to have that level of responsibility is hard.* [3]

It appears that being young added to the isolation of their roles, as young people do not have a large connection to the world outside their families. Being young in age and providing care also produced unnamed emotions, and made the task of "growing up" difficult to cope with.

One of the most common themes identified in "young carer" literature is the idea that these young people experience a "burden" by having to provide care for their parents. In contrast, the women in this study did not speak about feeling a burden; instead they indicated that they felt like they *were* the burden:

> *To me it wasn't a caring thing, it was removing some of what I thought was the issue, what was putting the stress on her [mother].* [1]

> *I feel like no matter what I'm doing someone is being let down, someone is having to take on more work than they can.* [4]

The participants felt that it was their responsibility to remove any burden from their mothers' lives; in this case it meant taking care of themselves.

"I don't know if there's a word for it"

In the interview I asked the women if they had a word or phrase they used to describe the support they provided for their mothers. Most of the women did not have an answer:

I don't know that I ever described my care for my mother, to anyone. And I don't know how I would have. [2]

I then told the women about the phrase "young carer" and how it has been used in the literature to describe their experience. None of them had ever heard the expression before. I asked them if they identified with the term "young carer" and also what it meant to them:

I guess it's probably like, just taking on more adult responsibility at a younger age. [1]

Sure yeah, I was a young carer, I was a parent to my mother. [2]

Um, I think that's how I would describe it, being responsible for her welfare. [3]

The fact that these privileged women, all current or prior university students, have never heard over the term "young carer" is interesting, and may suggest that most young people providing care are not "young carers" until they come in contact with a professional. Young people do not identify with term "young carer" and do not derive meaning from it. The participants' inability to describe their caring role also reveals that there is lack of (or a very small) discourse available for speaking about the experiences of young people who provide care. Having no words, and not knowing how to speak about something clearly contributes to the problem, as individuals do not identify with language

that is geared towards providing them support. Therefore using the term to speak about these young people contributes confusion to an already complex situation.

I will use an example from my own research experience to highlight how using inappropriate language prevents young people from engaging. In my recruitment poster for this study (see Appendix B) the criteria for the young person's parent was: "a parent in contact with the mental health care system". I felt that terminology was inclusive as it did not limit my sample to individuals with a formal diagnosis, and in addition I felt that this terminology did not totalize the person as their diagnosis. This was not apparent to the individuals who are not familiar with mental health care language, and read my recruitment poster. I received e-mails from potential participants who did not understand what "in contact" with the mental health care system meant. It is clear to me now that I would have been more successful in recruiting if I had simply said, "a parent with a mental illness". By using my flowery language articulated in a service-giving professional vocabulary, I may have prevented many individuals from participating in my research.

"Young Carers" Looking Back from Adulthood: Legacies and Future Possibilities

Continuing in my exploration of the participants' understanding of their caring role, I invited them to reflect on how their experiences shaped their identities as adults. The women indicated that providing care to their mothers was laden with both challenges and successes, but they saw their role as something "they had to do". The women felt that their experiences in providing care allowed them to become independent,

hardworking, and resilient as adults - so much that it influenced the direction of the careers and educations. Despite all that they had gained from their caring roles, the women admitted the isolation that comes along with a lack of vocabulary to talk about their experience and relate to others.

"It was a job that needed to get done"

One of the most striking themes in this study was the way the participants spoke about their caring experiences using the discourse of "work". Certainly some individuals speak about "work" in a positive, passionate way, but there was something about the way this group of participants used "work" language that allowed a degree of emotional detachment. These women spoke of "work" in terms of rational logic, that kind of "pull up your bootstraps" and "get through it" mentality:

> *There are the things that need to be done to keep the house somewhat functioning.* [1]

When speaking about providing care, the participants spoke about their personal qualities of independence, contrasting themselves to others individuals:

> *I was always, and I guess continue to be, the type of person that if there is a job that needs to be done I'll do it. So, mom needed some taking care of, I was there, I filled that role.* [2]

> *I've always been of the mindset that if there's an issue you deal with it, you don't just complain, you sit up and you do something about it.* [3]

The way the women speak about providing care suggests that they are in some ways separating their adult identities from the undesirable image of a dependent person- their mothers. Using the language of "work" may reflect again, the lack of available language with which to speak about providing care as a young person.

Resilience

In the interviews I noted that one area of "young carer" literature suggest that the young people "lose their childhood" and lose out on many opportunities by taking on responsibilities at such a young age, while another suggests that young people will be resilient, and more mature due to their caregiving experiences. Before I even finished explaining this range of options, some of the participants quickly told me that they were resilient:

> *I think that because I have had the experiences that I have, I've been able to excel.* [1]

> *I'm definitely on the mature and resilient end of the spectrum and I have no regrets, I wouldn't change my life.* [2]

In contrast, other participants did not endorse the resilience discourse with certainty:

> *I think maybe on the resilient side… I feel like I'm almost better equipped to deal with obstacles, that's how I feel anyway. I don't think I'm damaged by it.* [3]

> *I have problems with coping, like coping with stress and anxiety and I'm currently working towards dealing with those better… I would like to believe that children of parents with mental illness can come out okay, but, my experience has been mixed.* [4]

In addition to reminding myself not to present participants with constricting false dichotomies, I realized that "burden" and "resilience" are words used in the discourse of adults providing care, but are also relevant to young people. These participants knew the two terms, and were quick to take up resilience, or slow to admit they were unsure. In some of the interviews, participants communicated an urgency to convince me that they were "okay", that they weren't damaged by their experience. I wondered if that was about me, and how I identified myself at the beginning of the interview. Did the women think that I was on the "resilient and mature" end of the spectrum because I was researching this topic, and did they feel pressure to get there too? This was not something I thought about until it came time to analyze the women's stories. I was able to reflect on this with some of the participants during follow up interviews.

The Effect on Their Life

In addition to shaping their adult identities, the women in this study commented on how their caring experiences had influenced their educations and careers:

> *I've been able to use my experiences and been able to do projects on them, and been able to do readings on them, and learn what's in the research. And being able to learn about myself so all these projects I have done have been therapy sessions.* [1]

> *I work in mental health, and my passion for working in this field comes from my experience with my mother and watching her recovery. And being part of her recovery, and knowing that if my mother can move forward and experience wellness and quality of life, anybody can.* [2]

These comments suggest that the women want to put their experiences - good or bad - to use to help improve the lives of other people. They echo another research study indicating that social services workers are motivated by desire to repair damage in their own lives and the lives of others (Hoggett, Mayo & Miller, 2006). In addition, in follow up interviews the participants were not surprised at all by this result and the effect that the caring role had on all the women's lives.

I was hoping that by highlighting the lived experiences of these women, there would be an indication of what would have been useful for them during their time as young people providing care. In the interviews I asked a question along the lines of "looking back, what would you tell yourself then that you didn't know, but know now". The answers were very unique to each woman's situation:

> *If I knew that what we were dealing with was actual; it wasn't just us. It was other people have the same, or similar problems within their household. "You're not alone", like that would have probably been really beneficial. [1]*

> *I've been reading about having a parent with BPD and from that like, people have had the exact same experiences as me. So that made me feel a lot better, knowing that I wasn't crazy, that I wasn't completely alone with it.* [4]

I think due to my own experiences, I wasn't surprised that the participants wanted to feel like weren't alone in their situation. There is a certain degree of power in knowing that you are not alone. It somehow makes your tasks more bearable and gives you hope, even though rationally it doesn't change anything to do with your circumstances.

Slightly shifting topics, I explored what would have been helpful for the participants at the time of their caring. One of the women felt well supported by her faith and family, but the others provided these insights:

I'm sure that talking to someone would have helped I just know that I would have been really resistant to it… It's kind of hard looking back on it, and figure out what I was actually thinking. [1]

We all got counseling on our own through EAP or through school… but I think it would be really beneficial to go to a psycho-educational group or a support group of some kind to talk to people in the same situation. [3]

Interestingly, none of the participants stated that *not needing* to provide care in the first place would have been the most helpful. Instead, the women had various ideas about what might have been helpful for them at the time including speaking to someone, support/education groups, and more assistance for their mother in contact with the mental health care system. In all cases the women indicated that they hoped that their mother would begin to or continue to recover from her mental health issues. What was missing from their accounts was a clear course of action to better their situation. Instead the participants appear to have difficulty identifying what would have been helpful for them.

To conclude, the process of becoming and continuing as a caregiver proved to be extremely unique and complex. Many factors influenced why the women became carers including their female gender and their desire to protect their fathers from the caring role. This second section of findings reviews two major themes that appear in the interviews: privatization of informal care, and understanding the caring role. It was revealed that the women in the young caring roles kept their roles and their mothers' illnesses a secret due

to the need to appear normal and the bonds of loyalty. The findings show that the severity and type of mothers' mental illnesses had a significant impact on the mother-daughter relationship, and the experience of the young person providing care. Looking back on their experiences, the women indicated how they've integrated the independence and resilience gained from their caring role into their adult identities. The effect the caring role had on shaping the women's lives was explored revealing that their isolation - socially and discursively - was a source of difficulty, yet they were unable to suggest what might have relieved them.

4.0 DISCUSSION & IMPLICATIONS

In Canada, the broad issue of young people engaging in care giving responsibilities has only been recently recognized as a public concern (Young Caregivers Initiative Niagara, 2008). In fact, I was only able to find a few Canadian based studies

that looked at the experience of young people who provide care, and none focused centrally on young people who cared for a parent in contact with the mental health care system. Most of the research that I located originated from Britain or Australia (Aldridge & Becker, 1993). These "young carer" research studies have resulted in the development of supports for young people who provide care, but direct less attention to the systemic injustices underlying their experience (Lloyd, 2006). This study was designed to respond to the critical literature that challenges the dominant discourse of "young carers" seeking to include voices that other research studies may have excluded.

4.1 Departures from "Young Carer" Discourse

The first question explored in the analysis of these participants' experiences was why and how they came to assume the roles of carers as young people. I remember saying to my thesis supervisor that I wasn't getting the participants that I expected females who grew up with single, unemployed mothers. Despite the strong layering of gender dynamics in this topic, most of the literature dedicated a few sentences to the fact that women were primarily in both the caring and "dependent" roles. I was disappointed with the lack of exploration into this factor.

Although the participants were all women caring for a mother, this sample was so unique because the participants came from socioeconomically privileged families, and lived with another parent who was not in contact with the mental health care system. To some degree then, this study disorganizes the dominant imagery of a "young carer" – a young individual providing care because they have no other option, because no one else is

available to do so. Although some young people may find themselves caring due to these circumstances, the literature is not capturing the complex processes that have affected the particular women in this study. When questioning *how* it is that the participants negotiate caring roles with other siblings and their "well" parent, I was surprised that the women did not seem to have given the idea much thought.

Although only one participant indicated that being female influenced why she became a carer, gender appeared implicitly as a major factor that led women into their caring roles. The women in this study indicated that they were providing a great deal of support for their mothers, so that their father did not have to. Some of the participants worried about the effect their mothers' illnesses had on their fathers, and wanted to protect their fathers from the caring roles. Some did note that they felt that women had innate abilities to deal with difficult caring responsibilities. Overall, I did get a sense that the participants felt a different sense of obligation towards caring for family members because they were women (Finch, 1998).

Neoliberal reforms of social programs continue to reduce public support, with the increased reliance on loosely defined community resources and family involvement. As Teghtsoonian (2009) suggests, the issue is that these community resources are underfunded, yet expected to provide all the support that was once provided by public services. As a result caregiving and support responsibilities fall to family members, predominately women. Studies indicate that the population of "young carers" is comprised equally of females and males (Aldridge, 2006). This study suggests rather

differently that young women with alternative options choose to become caregivers due to family gendered obligations.

This is an issue of concern for social and public policy, and to continue characterizing informal caring as a gender-neutral activity denies women equality (Teghtsoonian, 2009). In order to change this patterned disadvantage, it will be imperative that "dependency" no longer be devalued as an unwanted exceptional circumstance and instead be understood as a part of being human, and that adequate public supports free women from the unpaid domestic realm (Finch, 1998; Kittay, 1999).

The second issue explored in the analysis of these participants' experiences was how the women understood their caring experience as young people, and how this has affected them as adults. The study's participants indicated that their caring roles and their mothers' illnesses were deeply rooted in secrecy, constructing their experiences as privatized. Some women maintained this secrecy even if they were never told to do so, as they emphasized a need to appear "normal" to the public. Other participants maintained secrecy due to extreme loyalty to their mothers, and their families. "Young carer" literature would suggest the need for secrecy comes from a fear of having their family be under the scrutiny of child welfare services. The women in this study did not express fear and instead, their motivation for secrecy appeared to come from societal norms that stigmatize mental health issues. This muting and privatization of experience was isolating as no one else really knew what they were going through.

The women in the study did not identify with the term "young carer" and had difficulty expressing in words what their caring roles were like. Some of the women did not even think that what they provided was care, meaning that their experiences will be missed in the current language. There are several possible consequences of this, with the first being that individuals may not recognize supports geared towards them (Keith & Morris, 1996). A more striking consequence was revealed when the participants' spoke of what they wish they had known at the time they were young and providing care. Most of them wanted to know that they "weren't alone" or that other people were going through the same experiences as them. This suggests that lack of language to speak about caring as a young person may have contributed to the participants' isolation, solidifying the privatization of the experience.

Another point of departure from the "young carer" literature was the way the participants' in this study spoke about "burden". A "burden" discourse is deeply associated with the dominant "young carer" image - that these children have to take care of their deficient parent (Becker, 2007). Interestingly, in this study the women did not feel burdened by providing care. Instead, the women felt that they themselves *were the burden*, and their goal in caring was to take the burden (their own care) away from their parent in contact with the mental health care system. The participants in this study did not want to be a dependent person, even to their parents.

In terms of talking about the caring role itself, the women spoke of it as if it was work or a job. Some of them described themselves as "stepping up" to do what needed to be done. This "work" language that the women used was not something that I had seen

before in "young carer" literature. In many ways, it is not surprising as that type of language is deeply carved into the neo-liberal political discourse. Extending their image of not wanting to be a burden, using "work" language may have been another way for them to distinguish themselves from the dependent positioning of their mothers. This impulse may reflect the unforgiving construction of "dependency" in neo-liberal culture.

Along with the "work" language, some of the women involved appeared to be very eager to tell me that they were resilient and better off with this caring experience, in other words seemingly to integrate many of their caring role characteristics into their adult personalities. It is appears from this study that their caring experiences have taught the women that in order to be socially desirable they need to be hard working, resilient and most importantly independent.

4.2 Methodological Considerations

Even with a small sample, it became immediately obvious to me that the mental health issue itself was one of the most significant factors shaping caring relationships. The nature of participants' caring roles appeared to be very dependent on the severity and type of mental illnesses that their mothers were experiencing. In this sample, two of the women's mothers had mild mood disorders, the other participants' mothers were diagnosed with a personality disorder.

It was clear that the women whose mothers had severe mental illnesses did not experience the same benefits in their caring relationship as others. These participants indicated more challenges in their caring role, and were more hesitant when describing

their resiliency. This suggests that they had in fact experienced burden, even though they did not explicitly indicate it. Another significant factor was when the participants' mothers first experienced mental health issues. If the women had known their mothers as having a mental health issue since birth, they were accepting of their roles, and spoke of more positive relationships. However, in contrast two of the participants saw their mother change to experience severe mental health issues later in their lives, and they experienced more of a "loss" feeling of the mothers they once had.

The significant effect that the mothers' severity and timing of mental illness has on the caring relationship suggests that in future research "mental health" should not be researched as a broad, or generalized concept. If a study's goal is to draw meaningful information about young people's caring experiences, then the nuances and specific details of each type of mental health issue should be separated. The small sample in this study included considerable variability; the participants' stories would be done more justice if they were divided based on the parental mental health issue. This would of course add to the challenge of recruiting given the already hidden nature of young carers, and would therefore not be suitable for a short-term study.

It is important to note the value of inviting "young carers" who are now adults to participate in this type of research. Initially, I considered talking to young people who were actually "young carers" at the time of the interview, but upon more reflection I decided to invite individuals who had the benefit of time to reflect on their experiences. Due to the lack of language available to describe "young carer" experiences, it may have been advantageous to speak with adults. Their insight from a distance produced rich and

textured stories, and suggests that this perspective may be an important focus for future research on "young carers".

4.3 Practice and Policy Implications

Currently, most social support and social services aimed towards "young carers" are being informed by research that suggests "young carers" are socially isolated and need a break from the burden of caring. This may be the case for some carers, and this study is certainly not trying to take away from the importance of their needs. Instead, this study suggests that for a certain subgroup of young carers, those types of support may not be very relevant. If the caring role is not a burden, and the women did not feel socially isolated at the time of caring, I wondered what would have been helpful for them. The women did acknowledge that peer-support and psycho-education may have been helpful, and some women wondered if they would have agreed to talk to anyone about caring when they were younger. Overall, the participants had difficulty articulating what they thought could have been helpful for them in their caring roles. What was interesting about the participants' reflections in this study was that the supports they thought of still involved them providing care for their parent. I was surprised that the participants did not say that their life would have been easier if their mother did not have a mental illness in the first place, but maybe the participants were more realistic than I am. All participants did indicate that they hoped their mothers would recover (or continue to recover) from their mental illnesses.

This is important knowledge for service providers who come in contact with a young person who is providing care for their parent. It may be beneficial for service providers to help "young carers" name their experience, and assure them that they are not "alone" in their responsibilities. In addition to connecting them to formal supports that the community may offer, the service provide should engage in family centered interventions, where the parent with the mental health issue, the "young carer" and the rest of the family can all sit down together (Moore & McArthur, 2007). The study suggests than an effective action a service provider can take to help a "young carer" is to advocate for the parent with a mental illness, and make sure they are getting the care they need from formal service providers. This has been mentioned in the "young carer" literature, but not often expanded upon (see Grant et al. 2008).

Why then does all the attention become focused on the "young carers"? I can sometimes get wrapped up in "young carer" literature and forget that I am researching mental health. This angle hardly seems to help the actual individuals with mental health issues, and this study suggests that the young people providing care are not benefiting from the "young carer" focus. Using an institutional ethnography lens I explored who benefits from naming and talking about "young carers" (Campbell & Gregor, 2002). Having children - or "young carers" as the face of the suffering population causes the public to sympathize with their needs, and put pressure on the government to help these young people. The victims become the young people - not the actual individuals with mental health issues. It is not expensive for governments to fund programs to support these young people (Lloyd, 2006). However, it is expensive for governments to provide

proper support for individuals with mental health issues. If the focus were actually on the insufficiency of the mental health care system in Canada, people would be asking instead "Why are these young people caring in the first place?"

Unfortunately, in a neo-liberal climate, it's "every woman and man for themselves" and mental health issues become an individual responsibility. If a young person needs to provide care to their parent, it appears to be the fault of their parent who was not able to have enough control over their illness (Olsen, 1996). This turns the public's attention towards "parental capacity" and attitudes begin to surface that question whether individuals with mental health issues should be having children. As a result, parenting with a mental illness becomes automatically linked to the risk paradigm (Edwards, 1995; Gladstone et al. 2006).

4.4 Conclusion

Situating this study back in the province of Ontario, the concept of young people providing care for parents with a mental health issue has received little attention; the most recent study done by Health Canada (2004) did not mention individuals under the age of eighteen. However, the Ontario government has been developing a 10-year strategy for mental health, and has established an advisory group with family members and individuals with mental health issues (Minister's Advisory Group, 2010).

In December of this year, this advisory group published its newest report. There was a loud silence on the topic of informal care providers as this report only recognized them as needing to be trained to identify mental health symptoms for early intervention. Young people are only referred to as recipients of service, and are in no way acknowledged for providing any care (Minister's Advisory Group, 2010). It is hoped that this paper will indicate that young people are providing care here in Ontario, they have a story to be told and behind it they have a parent who is not being properly supported by formal mental health care.

APPENDICES

Appendix A

Interview Questions: The Mental Health Care System and Young Carers

Katherine Schleicher, (Master of Social Work student)

(School of Social Work – McMaster University)

Topics to be included in the semi-structured interview are listed below:

1. Introduction Question: You've come forward as an individual who identifies with having a parent who is in contact with the mental health care system. Can you tell me how you have come to identify yourself in that way?
   a. Probe: When did you first become aware of your parent's illness, and what was your initial reaction?
   b. Probe: Who is in your immediate family, and how did this initially affect the relationships within?

2. How would you describe the support and care your parent needs in order to maintain their wellbeing.
   a. Probe: Were you aware of any supports your parents received (followed by mental health professionals, counseling, ect.)

3. How would you describe your involvement in providing care for your parent?
   a. Probe: Due to the fact that mental illness is often cyclical, can you describe what a typical "good day" and a typical "bad day" would be like for you in terms of your involvement with their care?
   b. Probe: What has your relationship been like with your parent during these times?

4. What kinds of insights, challenges and tensions have you experienced as you grew up?
   a. Probe: How did you identify with your peers?
   b. Probe: How did your care giving experiences shape your identity as a young person and as an adult?

5. Do you have any ideas that would have been helpful in sustaining your parents' and family's well being?
   a. Probe: Do you think the government has any responsibility in the well being of your parent?
   b. Probe: Would have any services specifically for you as a "young carer" been helpful during this time?

6. Looking back, what would you tell someone in your position that you wished you had known at the time?

7. Is there anything I haven't asked about your experience that is important for me know?

END

Appendix B

**PARTICIPANTS NEEDED FOR
RESEARCH IN MENTAL HEALTH CAREGIVING**

I am looking for volunteers who are 17 years of age or older to take part in a study
of individuals who for a significant period of time, provided primary care giving
responsibilities for their parent who is in contact with the mental health care system.
You would be asked to participate in an interview you will be asked to share reflections
on your experiences, and provide your ideas to better the situation of both parents and
young people who have these experiences.
Your participation would involve a maximum of two interviews,
each of which is a maximum of sixty minutes.
For more information about this study, or to volunteer for this study,
please contact:

Katherine Schleicher
Master's Student
School of Social Work
Email: schleikl@mcmaster.ca
**This study has been reviewed by, and received ethics clearance
through, McMaster Research Ethics Board.**

E-mail Kate: schleikl@mcmaster.ca	E-mail Kate: schleikl@mcmaster.ca	E-mail Kate: schleikl@mcmaster.ca	E-mail Kate: schleikl@mcmaster.ca	E-mail Kate: schleikl@mcmaster.ca	E-mail Kate: schleikl@mcmaster.ca	E-mail Kate: schleikl@mcmaster.ca	E-mail Kate: schleikl@mcmaster.ca	E-mail Kate: schleikl@mcmaster.ca	E-mail Kate: schleikl@mcmaster.ca	E-mail Kate: schleikl@mcmaster.ca	E-mail Kate: schleikl@mcmaster.ca	E-mail Kate: schleikl@mcmaster.ca

Appendix C

The Mental Health Care System and Young Carers

Letter of Information

The Canadian mental health care system has been significantly restructured over the past twenty years to "bare-bone" levels of care, meaning that it is often the responsibility of family members to provide care instead of paid professionals. When there are few family members able to provide this care, caring responsibilities can fall to the children of the individuals in contact with the mental health care system. I am interested in hearing these individual's point of view as adults in order to explore the experiences of young people in Canada who have provided a significant level of care for a parent who has been in contact with the mental health care system. I'm also interested in ideas these individuals have that can contribute to better sustaining them and their families.

I am seeking to interview students at McMaster University aged 17 and above, who identify as individuals who provided a significant level of care to parent in contact with the mental health care system. I am interested in hearing the point of view of adults who have been given time to reflect on their experiences, and gain important insights. Participants will be asked to take part in one interview in a private office, on campus in the School of Social Work. The interview will last approximately one hour, and the participants can choose a time that is most preferable. With permission by written consent, the interview session will be tape recorded and transcribed. Participants will also be invited to participate in a follow up interview where they will be provided an opportunity to reflect on, and review their interview transcript.

Although it is not likely, it is possible the information that participants share may focus on challenges or negative experiences in their life, and may be distressing. Participants may choose to not answer any of the questions. Participants may choose to withdraw from the study at any time without consequences. If participants choose to withdraw, all information they have provided will be returned to them or if they would prefer the data can be used for research purposes.

Participants will not receive any direct benefits from taking part in this study, but their participation may help to change the current structure of the mental health care system to provide better care for individuals and their caregivers. Participation in this research is voluntary and confidential. Every care will be taken to respect participants' privacy. No identifying information will be included in any of the written reports generated form this study, and all information provided will be locked in a desk at my home to which I only have access.

I expect to have this study completed by approximately August of 2011. If participants would like a brief summary personally, please let me know how you would like it sent to you. This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance.

If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

> McMaster Research Ethics Secretariat
> Telephone: (905) 525-9140 ext. 23142
> c/o Research Office for Administrative Development and Support
> E-mail: ethicsoffice@mcmaster.ca

I will be conducting interviews at (dates). To participate, please contact Kate Schleicher by the e-mail address or phone number provided below.

Thank you for your help.

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Appendix D

The Mental Health Care System and Young Carers

Consent Form

I agree to take part in this study. I have been fully informed about this study and I understand that its purpose is to understand the experiences of students at McMaster University who indicate that over a long period of time, they provided a significant level of care for a parent who is in contact with the mental health care system. I understand that Kate Schleicher is the principle investigator of this study, and that her work is being supervised by Jane Aronson (faculty member of the McMaster School of Social Work).

I am willing to take part in one interview that will last approximately one hour, and will give permission to have the interview audio-taped and transcribed. I understand that this interview will take place in a private office in the School of Social Work, and I have the ability to negotiate the specific time. I understand that I will also be invited for a follow-up interview, and have the right to decline this request. At the follow up interview, I understand that I will have the opportunity to review my interview transcript have the opportunity to ask to remove any information that I do not feel comfortable with.

Although it is not likely, I understand that it is possible that the information I share may focus on challenges or negative experiences in my life, and may be distressing. I understand that I may choose not answer any particular question and/or may choose to withdraw from participating in this study at any time. I understand that if I choose to withdraw any information I have provided, including audio-tapes, transcripts or notes will be returned to me or if I prefer the data can be used for research purposes.

I understand that I will not receive any direct benefits from taking part in this study, but my participation may help to change the current structure of the mental health care system and may inform practitioners of the unique needs, challenges and positive experiences of young people providing care for a parent who is in contact with the mental health care system.

I understand that my confidentiality in this study is assured, and this means that my name or any information that would allow me to be identified will not be used in research reports generated from this study. I understand that the information I provide will be kept in a locked desk where only Kate Schleicher will have access to, and that all information kept on a computer will be protected by a password. I understand that once the study has been completed, the data will be destroyed. I understand that if I have further concerns and questions regarding my rights as a research participant, I can contact the McMaster Research Ethics Board.

I have read the information presented in the information letter about a study being conducted by Kate Schleicher, a graduate student of McMaster University. I have had the opportunity to ask questions about my involvement in this study and have received the additional details I requested. I have been given a copy of this form. I agree to participate in the study.

_____   _____

Name and Signature of Participant   Date

_____   _____

Name and Signature of Investigator   Date

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