Fighting For Normlacy: A Critical Analysis of Family Caregivers' Perspectives on

Supports and Housing for a Family Member Living with Serious Mental Health

Issues

By

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Abstract

This thesis will critically discuss the relationship between family member caregivers of someone living with mental health issues and the housing and mental health system, within the Manitoba context. In a period when mental health and housing systems face financial constraints and limited resources, creating a responsive system that focuses on the needs of the individuals it serves requires not only identifying those needs but understanding the individuals and their perspectives. The focus of this thesis will be the exploration of nine family caregivers' views on providing supportive care to a family member living with mental health issues. Major themes from the interviews will be explored including fighting for normalcy, responding to burden and stigma, and housing and supports. The intent of this thesis is to gain a deeper understanding of the needs of family caregivers and how these needs can inform policies to provide a higher quality of life for their families.

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1.0 Introduction to the Thesis Project

1.1 Setting the Stage and Statement of Purpose

It is becoming common practice in mental health systems to incorporate consumer and carer involvement in all aspects of the provision of services for people living with mental health issues (Cleary, Freeman, & Waler, 2006; Lakeman, 2008). This reflects a move towards a system of care that is centred on the individual living with a mental health issue and their family members. In other words, a system that places an importance and value on actively engaging and involving them in shaping and evaluating the type of care that is provided. It is also widely accepted that despite this paradigm shift towards a discourse on patient and family focused care, the reality has not yet met up with the ideal (Cleary et al., 2006; Lakeman, 2008). Family members are still facing hurdles in accessing information, coordinating care, and being an integral part of the recovery process (Ward-Griffin, Schofield, Vos, & Coatsworth-Puposky, 2005). As a result, they experience marginalization, which in turn has negative impacts on overall family health.

Family member carers are an important constituency and can provide a different perspective on care issues than the individual living with a mental health issue – as defined as an individual with a chronic or severe mental illness – and the professional care providers (Lakeman, 2008; Holley, Hodges, & Jeffers, 1998; Friedrich, Hollingsworth, Hradek, Friedrich, & Culp, 1999). It is important to

understand that factors affecting the ability of family members to provide supportive care are varied and may include: stress, burden, sense of loss, access to information and housing, coordination of care, worry about care when they are gone, and financial stress. As is further discussed in Chapter 2, much of the literature on family member carers has focused on quantitative analysis of issues affecting family caregivers, but qualitative research focusing on family caregiver perspectives on such issues as housing and supports has not been fully explored (Ward-Griffin et al., 2005). In supporting processes of change within the community it is critical to gain a clearer understanding of how caregivers navigate issues and mitigate the impacts of these stressors.

Housing is a primary concern as people living with mental health issues face stigma and discrimination in accessing housing and are more likely than other groups to be homeless (Nelson, Sylvestre, Aubry, George, & Trainor, 2007; Trainor, Pomeroy, Pape, 2004; Friedrich et al., 1999). Housing is a key determinant of health, and access to decent and affordable housing is critical in supporting an individual living with mental health issues in their recovery processes (Ward-Griffin et al., 2005). Family caregivers play a key role by providing supportive care (e.g. emotional, advocacy, and financial supports) whether the family member lives within the family home or independently in the community. As a result, family caregivers are of central importance in the mental health and housing system by being an important housing provider and by supporting a family member living independently in the community.

The family's role as caregivers became increasingly important as care shifted away from institutional settings to the community setting, where families increasingly shouldered a greater part of the responsibility of providing primary supportive care (Dorvil et al., 2008; Friedrich et al., 1999; Ward-Griffin et al., 2005; Seeman, 2009). This more active role within formal systems of care did not occur rapidly or uniformly across jurisdictions and has had considerable impacts on overall family health and in particular on women, who have been the primary caregivers.

As a result, this project is based on an understanding that caregivers are an important element of care, that there are gaps in our understanding of their needs and priorities, that they represent a largely untapped source of information for system planners and that the existing data set provides an opportunity to explore what were the views on care of a sample of caregivers.

1.2 Theoretical Framework

The theoretical framework perspective for this thesis has its roots in the post-positive tradition of the social sciences which recognizes power relations, complexity, diversity, and discourse as being integral components of, and topics for, researchers to pursue. As a result, it rejects the role of the planner as being the objective applicator of scientific techniques in public policy and research (Allmendinger, 2002; contrast with Faludi, 1973). The history of planning for people living with mental health issues and their families and caregivers has been characterized by a rationalistic approach to public policy, which emphasized top-

down planning by professionals (Tomes, 2006). This approach has propagated feelings of disenfranchisement (Miliken & Northcott, 2003), reinforced stigma and discrimination (Jones, 2005), and further marginalized people directly affected by policies from the decision-making processes (Tomes, 2006). For people living with mental health issues it has resulted in increased poverty (Forchuk et al., 2007; Dorvil, 1997), homelessness (Browne & Courtney, 2007; Dorvil, 1997), and criminalization (Peternelj-Taylor, 2008); for families and caregivers it has resulted in increased burden (Nelson, et al., 2007; Dorvil, 1997), stress (Saunders, 2003; Dorvil, 1997), hopelessness (Jones, 2005; Rose, Mallinson, & Walton-Moss, 2002; Howard, 1997), and anger and frustration (Rose et al., 2002; Friedrich et al., 1999).

A rational planning theoretical framework approach to the issues mentioned above is ill suited to address them. Three major critiques of the rational planning framework and practices apply here. First, the notion of value-free, objective planning that can apply technical processes to resolve differing perspectives and conflicts that arise through the planning process is not possible (Klosterman, 1978; Harper & Stein, 1992). In other words, planning has never been devoid of values, politics, interests and ideologies where planners can separate the work they do from their own values, experiences and background. The assumptions researchers make and the scope of the issues they choose to examine are reflective of a normative view of the world and hence are political decisions.

Second, Allmendinger (2002) argues that rational planning is silent on "the role of power and discourse in the formation, interpretation and application of theory"

(p.27). The supremacy of the professional (social worker, doctor, nurse, psychologist, etc.) reflects a discourse within contemporary society that places a higher value on the knowledge and 'truth' of professionals over the experiences and knowledge of people living with mental health issues or their family caregivers (Foucault, 1961; Allmendinger, 2002). Addressing the structural issues that affect family caregivers requires research that is sensitive to power imbalances, structure, agency, and discourse (Allmendinger, 2002). This thesis will seek to explore other 'truths' and 'ways of knowing' by drawing on and exploring the perspectives and experiences of family caregivers.

Third, the planner, as an objective applier of planning techniques and processes, creates what Allmendinger (2002) calls a paternalistic relationship between the planner and the public. This approach to planning fosters and undemocratic environment where groups are planned *for*, not *with*. In its processes, rational planning methods ensure that decision-makers (such as the medical professionals identified above, as well as, planners) assume almost complete control over decision-making processes, to the exclusion of those affected by the decisions (Etzioni, 1967). As a result, rational planning marginalizes people affected by policies and does not recognize their legitimacy as decision-makers, primarily because of their lack of technical expertise.

Further, conducting research that involves a group that has been traditionally marginalized from the policy decisions that have affected it requires an approach that respects and recognizes the group's legitimacy to be involved and participate in

those processes, and the research that informs and shapes that discourse. As Cordova argues, "as we speak of improving the planning process, we must ask questions about what it will take to ensure the participation and influence of those who in the past have been the victims of that process" (Cordova, 1994, p.242). In other words, how will planners ensure that family caregivers will have an opportunity to be a part of the research, planning, implementation and evaluation of actions and policies that directly affect them?

A collaborative approach to planning research seeks to explore and examine agency and structure within society. The concepts of 'agency' and 'structure' are central to the collaborative planning approach; notions that have their roots in the works of Habermas and Giddens (Healey, 1997). Structure (society and its institutions) both shapes and is constructed by agency (individuals) through discourse (Allmendinger, 2002). Discourse among individuals and within society is important to how we perceive truths and create norms, or as Allmendinger (2002) states, 'to make sense' of the world around us. Power dynamics and relations within society exert the primary influence on discourse and knowledge (Allmendinger, 2002). In our current political economic system, power is exerted through the various professions and disciplines within society and regulated and managed according to laws, policies, systems and networks (Painter, 1995; Allmendinger, 2002). According to Allmendinger (2002), professions become 'judges of normality' by initiating and controlling discourse and regulating action.

According to Patsy Healey and colleagues, planners can play a collaborative role in changing the discourse, policies, rules, and ways of thinking about issues in hopes of changing 'processes and outcomes' (Healey, Khakee, & Motte, 1997). As a result, the collaborative tradition seeks to understand how power dynamics operate within structure and agency and how individuals operate, struggle and create discourse and affect structure, and through this raised awareness, seek avenues where further action or research may be needed (Healey, 1997; Allmendinger, 2002). This thesis will be informed by the collaborative framework of planning by engaging family caregivers, amplifying their voice, sharing their perspectives, exploring how they are impacted by the structures and how they actively engage to help shape their world, and seeking to understand what they need to help alleviate (mitigate) the burdens associated with the caregiving process.

1.3 Assumptions and Limitations

The theoretical and methodological approach for the research of this thesis rests on a set of assumptions. I chose collaborative planning as the theoretical framework for this thesis because it reveals assumptions, myths, ideologies and power structures represented in discourse and texts. I understand that family members have traditionally been excluded and marginalized from the discourse on how to provide care for someone living with a mental health issue, and I assume that analysis of interviews with them will reveal issues, such as marginalization, burden and power inequalities between family members and professionals within the mental health and housing system. A qualitative methodological approach, which uses Critical

Discourse Analysis as a means to analyze data, tries to be explicit about the assumptions of the researcher. As a researcher, I play a role in examining and constructing narratives; as Richardson (1990) states, "[researchers] weigh and sift experiences, make choices regarding what is significant, what is trivial, what to include what to exclude" (p.152). In other words, it is important to be aware of my own identity as well as the knowledge, experiences and biases I bring to the research.

There are a few intentions and limitations of the study that should be explicitly highlighted. First, the number of interviews analysed represents a small sample of the overall family caregivers within the Winnipeg context. Thus the study has been organized to understand the narratives of a sample of family member caregivers rather than to generalize beyond those who participated in the interviews. Second, family caregiver interviewees were recruited from local community mental health agencies and family support networks and therefore may not be representative of caregivers who have not had access to similar community sources. Finally, the interviews were conducted at a specific point in time and participants were asked to recall past situations. I am not aware of any current events that may have had particular influence on participant's contributions to the study; nevertheless, a longitudinal study may have provided a more thorough analysis of caregiver perceptions over time. Despite these limitations, the study will contribute to our understanding of caregiver experiences within the mental health supports and housing context.

1.4 Significance of the Research

The major contribution of this thesis is to advance the level of understanding of the perspectives of family caregivers in relation to the mental health and housing system and to their significance as a primary stakeholder. This project is important because family members are often the primary caregivers and source of support for someone living with mental health issues, and often feel first-hand the impacts of inadequate support; yet their role within that system is often marginalized. By analyzing family member interviews, this project will add to the literature and further a dialogue that supports processes of transformation which strive for a system of care that places people living with mental health issues and their families at the centre. Qualitative research which explores the complexities of the caregiving process through the words of the caregivers is a step towards initiating that dialogue.

1.5 Chapter Content

Chapter 1 – Introduction to the Thesis Project

This section provided an introductory glance into and statement of purpose for the research project. It also provided an account of the theoretical framework that guided the research. Assumptions and limitations of the research were also identified to provide the reader with a better understanding of the research project. It also described how this research project can help to continue the dialogue with

policy makers on issues impacting a population that has been traditionally left out of the conversation on policies directly affecting it.

Chapter 2 - Literature Review

This chapter intends to provide the reader with an understanding of the current body of literature on family caregivers with a particular focus on issues of support, burden, stigma, caregiver perspectives and housing. This review critically explores the historical, structural context that has contributed to the current environment where family caregivers act. It also identifies gaps in the literature.

Chapter 3 – Methodology

This chapter describes the research methodology for analyzing family caregiver texts. This section includes a review of Critical Discourse Analysis and its use as an approach to explore family caregiver texts.

Chapter 4 - Analysis of Interviews

Through the use of Critical Discourse Analysis, this chapter will discuss the results of the data analysis process. This section will also review the themes of Fighting for Normalcy, Stigma and Burden, and the Centrality of Housing that were identified in the interview texts.

Chapter 5 - Discussion and Recommendations

The final chapter will discuss the insights from the data analysis and provide a more thorough in-depth review of the themes in relation to housing and supports within the literature on housing and mental health systems. Implications from the discussion section will suggest ways in which findings from this project can inform future research in the area of family caregivers. This section concludes with recommendations for informing public policy.

2.0 Literature Review: A Discussion of Family Member Caregiving

It is important to provide a contextualization of how we got to where we are today in our social structures and to review the research on family caregivers to better understand their perspectives on how a system can be more responsive to the care needs of people living with mental health issues, their families, their support networks and their primary caregivers. To create that system that is more responsive and flexible to the various needs and demands placed upon it, we need to better understand family caregivers themselves, the role they play in the mental health and housing system, the nature of the caregiving process and how they are both impacted by and impact the structure. The following section discusses the processes of deinstitutionalization, its influences, systemic context, and impacts on people living with mental health issues and their families. The remaining sections of the literature review are intended to provide an insight into family caregivers through the current body of knowledge by discussing deinstitutionalization and its impacts, such as burden, housing, caregiving, stigma, and the mediating factors in the caregiving process.

2.1 Processes of deinstitutionalization

Deinstitutionalization has had an enormous impact on the lives of people living with a mental illness and their families (Lauber, Eichenberger, Luginbuhl, Keller, Rossler, 2003; Baronet, 1999; Loukissa, 1995). A major criticism of the institutional model of care is the 'warehousing' of people living with mental health issues, placing them in

an environment where they received standardized care, experienced loss of control over treatment and housing, and felt the effects of stigmatization, and the restriction of choice on types of care and housing (Ridgway & Zipple, 1990). The next section will quickly look at the nature of deinstitutionalization, and how it occurred in North America and Europe before exploring how it continues to have an impact on the lives of people living with a mental illness, their families and their primary caregivers.

Deinstitutionalization Defined

It is generally understood among researchers that deinstitutionalization is composed of three core elements. First, there is a shift of treatment from psychiatric hospitals and other institutionalized systems of care into the community, second there is a concentrated effort to divert people with mental health issues from gaining hospital admission, and finally an investment in alternative community-based care that supports the individual in the community setting (Dorvil, 1997; Accordino, Porter, Morse, 2001; Bachrach & Lamb 2001; Kreig, 2003; Novella, 2009).

This change in the locus of care from the hospital to the community has resulted in the creation of a new network of support, which includes social workers, case managers, peer support groups, family and friends. However, this process of transformation to a community setting of care has not been uniform or linear across jurisdictions (Edgar & Doherty, 2001). It would be more accurate to speak of this

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transformation in terms of 'processes'; this would reflect the uneven nature of the shift away from the institutional approach to care.

European Experiences in Deinstitutionalization

The catalyst and nature of the transformation in how we care for people living with a mental illness differs greatly depending on the local institutions and dynamics that have helped shaped the paradigm shift towards policies of deinstitutionalization. As a consequence, different countries have all undergone their own unique processes of deinstitutionalization (White, 1996; Edgar & Doherty, 2001; Novella, 2009). This is due in great part to the differences in the role of government policies and legislation, the differences in social welfare policies, and the differences in the strength of family care and non-governmental organizations (Edgar & Doherty, 2001; Novella, 2009). In countries such as Denmark and the United Kingdom, 'normalization' is embedded within their social welfare policies and legislation at a national level. In Austria, deinstitutionalization within the country occurred unevenly because "decentralization along provincial lines for housing, for social welfare and for the organization and delivery of services for homeless people [resulted in] an uneven development of services between and within provinces" (Edgar & Doherty, 2001, p.66). In other countries, such as Greece and Ireland, deinstitutionalization has not moved as far towards the principles of integration and 'normalization'. Edgar and Doherty identify that in these countries people living with mental health issues rely more heavily than in other European countries on family care and non-governmental organizations, which are primarily church-based,

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as mediating factors between homelessness and institutionalization (Edgar & Doherty, 2001).

Despite these differences in processes of deinstitutionalization, Novella (2009), in his comparative review and assessment of the major changes in the delivery of mental health care services in North America and Europe, argues that there are some common threads between many of the countries in Europe and North America. A more recent convergence of policies and objectives has come as a consequence of some common pressures such as demography, epidemiology, developments in science, medical demand and public expectations (Novella, 2009; Shera, Aviram, Healey, & Ramon, 2002; Mechanic & Rochefort, 1996). Moreover, Novella asserts that this 'cross-national character' of psychiatric care and mental health policies can be characterized by: an expansion of the scope of psychiatry, a decline and change in the nature of the 'asylum', the development of alternative forms of care (including the diversification of services), new challenges of chronic mental illness, therapeutic developments, sub-specialization of psychiatry, and the change in the forms of coercion (Novella, 2009). In addition to the similarities in the characterization of the transformation of the mental health services there is also a 'cross-national character' in the impacts of these processes of deinstitutionalization on the individuals with mental health issues and their families. These impacts include increased homelessness and poverty, poor living conditions, increased responsibilities for families and caregiver burden, and trans-institutionalization (Novella, 2009).

North American Experiences in Deinstitutionalization

Similar to the European context, a common characteristic of the processes of deinstitutionalization across North America has been the massive closure of hospital beds since the 1960s (Dorvil, 1997; Sealy & Whitehead, 2004; Dorvil, Maurin, Beaulieu, & Robert, 2005). By looking at bed closures within psychiatric hospitals, as a measure of the pace of deinstitutionalization, we can see that they occurred in different places at different times. Bed closures in the U.S. began after 1954 and continued to see dramatic declines in the mental health population in both state and county hospitals to 1998. During this time span, the population decreased from approximately 553,979 to 61,722 respectively (Geller, 2000). The total number of psychiatric hospitals also declined during this time by 102 (Geller, 2000).

In Canada, policies of deinstitutionalization occurred unevenly primarily because of the provincial jurisdiction over health care, which limited a national approach. For example, looking at bed closures, Québec undertook the elimination of approximately 4,241 places in psychiatric hospitals between 1971 and 1986 and the elimination of another 3000 beds between 1997 and 2002 (Dorvil et al., 2005), whereas in Ontario, most of the bed closures occurred between 1965 and 1968 (Forchuk et al., 2007). In all, between 1960 and 1982, the population within psychiatric hospitals in Ontario declined from 19,501 to 4,514 (Forchuk et al., 2007). Further, Sussmann (1998) in a study examining the evolution of psychiatric facilities across Canada determined that inter-provincial cooperation and communication were limited and that, in many cases, the newly created alternative

community programs were merely mini-institutions (Sussmann, 1998; Forchuk et al., 2007).

In addition to transferring some of the institutionalizing effects of the psychiatric institutions to the community setting, in many cases, hospital bed closures were matched neither with a corresponding increase in investment in community based care nor with support services or housing in place (Shera et al., 2002; Sealy & Whitehead, 2004).

In addition to the lack of appropriate funding shifting to the community setting, other issues affected the success of deinstitutionalization policies. For example, health care planners didn't take into account some of the mediating factors that help individuals with mental health issues to live successfully in the community such as having access to housing and the presence/absence of supportive families and caregivers. This resulted in an increase in homelessness (Accordino et al., 2001).

Although there were provincial differences, throughout Canada, people living with mental health issues and their families experienced similar deinstitutionalization policies and outcomes. Since the 1950s, governmental health policies shifted away from the use of public mental health hospitals as the source of patient care towards community-based services. The primary growth in community mental health services occurred in the 1970s (Sealy & Whitehead 2004; Shera et al., 2002).

Forchuk et al. (2007) in their review of housing, income support and mental health services, found that as psychiatric bed closures increased, the level of funding for community services struggled to keep up with the resulting demand. Their review

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also found that as the responsibility for social housing was offloaded to the provinces and municipalities, people living with mental health issues were increasingly marginalized in the housing market due to their dependence on personal economic resources and income supports. The structural disconnect between housing, income and mental health policies (i.e., deinstitutionalization) has been the major contributor for people living with mental health issues being at a high risk for homelessness.

In Québec, the rapid pace of psychiatric bed closures combined with the slow transfer of resources to the community setting, placed people living with mental health issues at a greater risk of being homeless (Dorvil, 1997). Deinstitutionalization also shifted the burden of care to families as bed closures often meant a transfer of care from the hospital to the family (Dorvil, 1997). For example, in 1985, of the 4,191 outpatients at Louis-H. Lafontaine Hospital, 62% lived at a relative's home (Dorvil, 1986; Dorvil, 1997).

A quantitative study by Sealy and Whitehead (2004) attempted to assess the process of deinstitutionalization across Canadian provinces as measured by decrease in the number of beds within psychiatric hospitals, the change in hospital beds devoted to psychiatric patients in general hospitals and provincial expenditure on out-patient community-based services. Their findings reinforce what has been reported in the literature above, namely that there is an uneven approach across jurisdictions (i.e. provinces) when it comes to implementing policies of deinstitutionalization. Investment in community-based services often lags behind

reductions in mental health beds, and deinstitutionalization is an ongoing process that doesn't end once the beds have been closed (Sealy & Whitehead, 2004).

Catalysts for deinstitutionalization

Many factors have contributed towards policies of deinstitutionalization within the North American context. The confluence of factors includes a growing awareness of the conditions and treatment of people living with mental health issues within the psychiatric institutions, legal challenges to the treatment they received, and the opportunities that advances in pharmaceutical drugs provided for people to manage the symptoms of their illness. In addition to these direct factors, governmental financial resource constraints and the cost factors associated with institutionalized care provided an additional rationale for seeking cost savings.

According to Kreig (2003), there are three important catalysts for transforming the paradigm in North America. They include humanitarian concerns about institutionalization, the defence of minority rights and the development of new drugs (Dorvil, 1997; Kreig, 2003). Court cases in the United States in the 1960s and 70s helped to shape and solidify the rights of people living with a mental illness. A Supreme Court case in 1960 (*Shelton v. Tucker*) ruled that involuntary institutionalization could only occur if there were no other available means to treat the individual living with mental illness; this would make it unconstitutional to deny psychiatric patients the right to live with their family or in a residential care unit if the level of care would be comparable (Kreig, 2003). The *O'Connor v. Donaldson* Supreme Court case of 1975 ruled that involuntary institutionalized non-dangerous

people living with mental illness have the right to be treated or discharged (Geller, 2000; Kreig, 2003). The early development of new drugs (such as Thorazine in 1955) permitted a wider range of people living with mental illness to live independently and outside of the psychiatric hospitals (Kreig, 2003).

In addition to the above mentioned factors that have helped shape the processes and policies of deinstitutionalization, Geller (2000) adds that in the United States context, the major impetus for shifting away from state-run psychiatric hospitals – as the primary location of care – was a combination of a lack of financial resources and the ability of states to upload the cost of care to the federal government through Medicare, Medicaid, Supplement Security Income and other federal grants (Geller, 2000). Further, a multi-country review of mental health system reforms in Canada, Australia, Britain, and the United States, by Shera, et al. (2002), points to cost containment pressures experienced by these countries as a primary driver for health and mental health reform.

The literature examining the causes and processes of deinstitutionalization has not focused on the role that families played in shaping the changes to the mental health system. Tomes (2006), in her review of the consumer survivor movement in the United States, argues that families and consumers have not had a major impact on policy change in mental health service delivery in that country. Tomes, further argues that the rise of the consumer/survivor movement arose in the 1970s as a response to policies of deinstitutionalization and restructuring put in place by the professional fields (i.e. psychiatrists, lawyers, and academics). However, the author

points to this movement as the first step towards gaining influence and that in recent years, consumer and family groups have been able to successfully affect some change in legislation and policy for the delivery of mental health services (Tomes, 2006). Similarly, according to Sharfstein and Dickerson (2006) in their review of the psychiatry and consumer movement, noted, "although having a limited impact on major policy shifts, [consumer and family movement] have had a major impact on the practice of psychiatry and other mental health services." (Sharfstein & Dickerson, 2006, p.734).

Section Summary

Deinstitutionalization, as defined by moving the locus of care from the institution to the community; by discouraging inpatient care; and by increasing the provision of alternative methods of service delivery, occurred both in North America and Europe. The character, pace of transformation and policies associated with each country's deinstitutionalization experience depended largely on the local structural and cultural context. Despite the local differences in deinstitutionalization policies, the contextual trends such as demography, epidemiology, developments in science, medical demand, and public expectations, have helped to shape certain similarities in outcomes for people living with mental health issues in countries that have undergone processes of deinstitutionalization.

These processes of deinstitutionalization in the North American context were largely the result of factors associated with a growing awareness of the conditions in

institutional facilities and legal pressures on the standards of care for people living with mental health issues, the growth in pharmaceuticals and national governments attempting to control costs. Next we will discuss the reasons for the shift in policy concerning, how and where, we treat people living with mental health issues.

2.2 Deinstitutionalization and its impacts

It is important to look back at the processes of deinstitutionalization because the roots of many of the issues that people living with a mental illness and their families face are found in the processes of that transition. As indicated above, the shift of treatment from hospitals or institutionalised systems of care to community-based care occurred over the last 50 years in North America (Dorvil, 1997), and this shift in the location and type of care provided did not occur with a corresponding shift in resources. This lack of resources placed a heavy burden on community support networks and continues to have serious implications for people living with mental health issues and their families. For people living with mental health issues, there is a lack of community supports and access to decent and affordable housing (Friedrich et al., 1999).

There are many impacts resulting from the change in the place of treatment and the type of care, but for the purposes of this project, this section will focus on trans-institutionalization, housing and homelessness, the criminal justice system, and impacts on families.

Trans-institutionalization

As discussed above, deinstitutionalization, as a framework and a set of policies, has been applied unevenly across jurisdictions. This lack of a universal approach to deinstitutionalization has led some to question the use of the term since the outcomes of this process have not necessarily translated into better quality of life outcomes for people living with mental illness (Novella, 2009; Geller, 2000).

Such critics argue that what has primarily occurred is a process of trans-institutionalization (Geller, 2000). Trans-institutionalization is commonly referred to as the displacement of institutionalized methods of care from the 'institutional' setting within psychiatric hospitals to the community setting, such as group homes or foster homes (Geller, 2000; Kreig, 2003; Novella, 2009). In other words, as psychiatric hospital beds were closed, and access to in-patient care at hospitals was discouraged, a dispersed model of institutionalization occurred in the community due to a lack of financial resources, staffing and standards of care.

In the Canadian context, Sealy and Whitehead (2004) tried to quantify trans-institutionalization by looking at it as a function of a lack of investment in community services and the numbers of days of care in psychiatric facilities and psychiatric units in general hospitals. Between 1960 and the 1990s, they found a high degree of variation among regions and provinces. As a consequence, they found that "trans-institutionalization is a major component in the transition from institutionalization to deinstitutionalization" (Sealy & Whitehead, 2004).

In Québec, as a means to rehabilitate and avoid the "institutionalization" of people living with mental illness there was a policy direction to fund foster homes where people living with mental illness could integrate into a 'normalized' family situation (Dorvil, 1997). A 1972 evaluative study by Murphy observed that foster homes did not provide the desired social rehabilitation outcomes and were often characterized by conformity and a lack of independence, and in many instances were as institutional as hospital settings (Murphy, Pennee, & Luchins, 1972). A 1984 study by Dorvil had similar findings, concluding that "many such homes are mini asylums where the mentally ill are leading a vegetable life (to eat, to sleep, to sit, or to pace all day…)" (Dorvil, 1984 in Dorvil, 1997).

Due to the unevenness in the application of deinstitutionalization policies across North America, and in particular, the lack of investment in community services to off-set and complement the reduction in in-patient psychiatric beds in psychiatric institutions, many people living with mental health issues are in mini institution-like settings. As a result, trans-institutionalization poses a major challenge for mental health and housing reformers to address.

Homelessness

One of the biggest failures of deinstitutionalization has been the inability of planners and policy makers to address the growing the number of people living with mental health issues who are homeless (Bachrach & Lamb, 2001). Largely as a consequence of a lack of resources being transferred into community care initiatives and

programmes in communities across North America, people living with mental health issues became a growing segment of the homeless population and had increased involvement with the judicial system (Bachrach & Lamb, 2001). As a result, people living with mental health issues that are homeless have a diminished quality of life (Folsom et al., 2005), and are at increased risk of violence (Wenzel, Koegel, & Gelberg, 2000) and early death (Hibbs et al., 1994).

People living with mental health issues are over-represented in the homeless population relative to other groups. It is difficult to determine the exact number of people who are homeless who live with mental health issues; however the research shows that the numbers are significant. For example, a study assessing the psychiatric symptomatology and mental health service needs of 250 shelter users in Calgary found that 75% of those interviewed showed psychiatric symptoms and approximately 33% lived with a serious mental health issue (Stuart & Arboleda-Florez, 2000).

Similarly, a quantitative and qualitative study, as part of the Pathways Into Homelessness project in Toronto that interviewed 300 users of homeless shelters in Toronto, found that approximately 66% of those interviewed had a lifetime diagnosis of mental illness and that there were no significant differences in the characteristics of the individuals who were homeless for the first time and those who have been homeless previously. Both groups had significant histories of substance use, family histories of mental illness, and high rates of mental and physical illness (Goering, Tolomiczenko, Sheldon, Boydell, & Wasylenki, 2002).

Also, a 2008 report from the US Department of Housing and Urban Development providing national estimates on the number of sheltered and unsheltered homeless population found that approximately 28% of the sheltered homeless population had a severe mental illness. Further, a systematic review of the literature on the rates of schizophrenia in the homeless population since 1966 found that the prevalence of schizophrenia ranged from 4.4% to 16% and the weighted average (by sample size) of 10 studies was 11% (Folsom & Jeste, 2002).

There are many pathways into homelessness and the literature accounts for risk for homelessness as a combination of structural and individual vulnerability factors. The distinction will be adopted here, though clearly the two types are linked because conditions on the structural side can foster or mitigate individual circumstances. Structural factors include: declines in low-cost housing (Cohen, 1994; Sullivan, Burnam, & Koegel, 2000; Morrell-Bellai, Goering, & Boydell, 2000; Forchuk et al., 2007), increased rates of poverty (Sullivan et al., 2000; Morrell-Bellai et al., 2000; Forchuk et al., 2007), and reductions in social assistance rates (Cohen 1994; Sullivan et al., 2000; Morrell-Bellai et al., 2000; Forchuk et al., 2007). Individual vulnerability factors that increase the risk of homelessness for people living mental health issues include: substance use (Sullivan et al., 2000; Morrell-Bellai et al., 2000; Folsom et al., 2005; Schutt et al., 2009), childhood trauma, abuse (Sullivan et al., 2000; Morrell-Bellai et al., 2000), history of poverty, a breakdown in social networks, lower educational levels (Stuart & Arboleda-Florez, 2000), and lower employment levels (Stuart & Arboleda-Florez, 2000). Effects vary across

ethnic groups, underscoring the linkages between structural and individual factors (Folsom et al., 2005; Montross et al., 2005; Schutt et al., 2009).

Further, the homeless who have mental health issues are at a higher risk than the homeless without mental health issues of having more severe individual vulnerability factors. In this sense, the vulnerability is not only expressed in the breadth of the issues that people face but also in the depth of their severity. For example, a quantitative study by Sullivan, et al., (2000) looking at pathways to homelessness for people living with mental health issues found that such people were more likely to come from a household with a higher degree of family and income instability; were 60% more likely to have a family caregiver that is disabled (either mentally or physically); or were more likely to have a background of physical and sexual abuse. The study concluded that the homeless who have mental health issues "receive a 'double dose' of disadvantage – poverty with the addition of childhood family instability and violence" (Sullivan et al., 2000, p.444).

Additionally, a qualitative study of 29 homeless people in Toronto sought to understand how people become homeless and why some individuals remain homeless for an extended period of time or become chronically homeless. The study found that there are significant systemic or structural factors that contribute to homelessness including poverty, lack of employment, low welfare wages and lack of affordable housing. Micro related factors at the individual level include mental health issues and related substance abuse problems and childhood physical abuse or neglect (Morrell-Bellai et al., 2000). Additionally, of those interviewed, those who

had a serious mental illness (psychotic disorder) all reported that severe episodes related to their mental illness had a direct impact on them becoming homeless (Morrell-Bellai et al., 2000). Having more risk factors makes it more difficult for them to adjust to or negotiate changes in structural factors, such as adapting to a decline in the availability of low-cost housing options by relying on support networks or personal resources.

The relationship between homelessness and mental health can be stronger or more prevalent depending on the socio-cultural context and the ethnic group (Cohen, 1994; Guarnaccia, 1998; Folsom et al., 2005; Schutt et al., 2009). A quantitative study looking at homelessness and substance abuse among schizophrenics of Euro-American, Latino and African-American descent found that the collectivist characteristics of social support networks among immigrant Latino populations had a positive effect in reducing co-morbidity and homelessness rates relative to Euro-Americans and African-Americans (Schutt et al., 2009). The homelessness outcomes of different ethnic groups raise important implications for service delivery models in ethnically diverse cities or regions. The needs of the individual and the families may differ depending on different ethnic, cultural and socio-economic context of these stakeholders.

Criminalization

Studies looking at the relationship between deinstitutionalization and the criminal justice system can be found as early as the 1970s (Swank & Winer, 1976; Stelovich, 1979). Concerns were raised that a lack of resources flowing into the community setting for building and enhancing adequate support systems and personalized community treatment plans would, in the wake of large reductions in the number of psychiatric hospital beds, result in the criminal justice system replacing the psychiatric hospital as the place of last resort (Borzecki & Wormith, 1985; Bachrach & Lamb, 2001). This process of "placing mentally ill persons who have committed minor crimes into the criminal justice system instead of into the mental health system in psychiatric hospitals or other psychiatric treatment facilities" is referred to as the 'criminalization' of people living with mental health issues (Hoffman, 1990; Aderibigbe, 1997).

Evidence in the literature directly linking policies of deinstitutionalization with the 'criminalization' of people living with mental health issues is not conclusive (Teplin, 1983; Davis, 1992; Bachrach & Lamb, 2001). The conflict in determining the link, Bachrach and Lamb (2001) argue, is in quantitatively comparing the increase in the number of people with mental health issues that have been incarcerated pre and post deinstitutionalization (Bachrach & Lamb, 2001). The difficulty lies in getting data on the numbers of people with mental health issues in jails and prisons prior to deinstitutionalization to provide a comparison. Despite this lack of comparative data, the literature has shown that since deinstitutionalization there have been a large number of people living with mental health issues within the criminal justice

system and that this number has been growing (Aderibigbe, 1997; Bachrach & Lamb, 2001; Lamb, Weinberger, & Gross, 2004).

A report by the United States Department of Justice completed in 2006 identifying the prevalence of people living with mental health issues in the United States criminal justice system found that people living with mental health issues were overrepresented across the board within local jails, state prisons and federal prisons. The report found that people with symptoms of serious mental illness (e.g. bi-polar disorder, schizophrenia, and depression) accounted for 64% of local jail inmates, 56% of state prisoners and 45% of federal prisoners (James & Glaze, 2006; Peternelj-Taylor, 2008). The report also found that women with mental health issues were overrepresented in the incarcerated population compared to men (State prisons: 73% of females and 55% of males; local jails: 75% of females and 63% of males).

In Canada, the numbers are significant but not has dramatic as in the United States. In a comparative study assessing the 'criminalization' of the mentally ill in Canada and the United States, Davis (1992), found that Canada had high rates of mental illness in prison and jail populations but that more people with mental illness were diverted from the criminal justice system than in the United States, where resources are lower (Davis, 1992).

The experience of people living with mental health issues within jails and prisons is not positive. People living with mental illness are more vulnerable than other populations to suffering beatings, and other physical and psychological abuse in

prisons. This has a negative impact on their ability to cope with their mental illness (James & Glaze, 2006; Lefley, 2000; Peternelj-Taylor, 2008).

There are a variety of reasons why people living with mental health issues have increasingly been entering the criminal justice system instead of the mental health system. The main reason has been the failure of deinstitutionalization policies that have largely focused on bed closures and ignored the need for investments in community support services. Jurisdictions have been successful in closing institutional beds and diverting people from hospitals seeking short to medium term care, but they have not been as successful in providing community-based care that is personalized and that meets the needs of the individual.

Section Summary

Deinstitutionalization is an ongoing process that has at its core shifting the focus of care to the community while reducing reliance on institutionalized forms of care to treat people living with mental health issues. This change in mental health care delivery has not been uniform across jurisdictions and has varied both in place and in time, in relation to the local institutional and cultural context.

Despite the differences in the details of some of these policies, countries in Europe and North America have had similar outcomes both in terms of the type of services provided but also in the structural issues that people with mental health issues and their families face. These include a lack of governmental commitment to investing into the provision of adequate community based services, and a focus on closing

psychiatric beds and diverting people from in-patient care. Outcomes in these countries have shown people living with mental health issues have experienced, amongst other issues, overrepresentation within the homeless population and criminal justice system, and marginalization within the housing sector. As a result, many of the criticisms levelled at deinstitutionalization are not aimed at its conceptual core, but stem from its inadequate implementation. Next, this project will explore in greater depth impacts on families and caregivers.

2.3 Impact on family members

Deinstitutionalization, with its focus on a transition to community care, has resulted in families taking on greater responsibility over the caregiving process (Fleury, Grenier, Caron, & Lesage, 2008; Baronet, 1999; Loukissa 1995; Howard, 1994; Dorvil, 1997; Ward-Griffin et al., 2005; Milliken & Northcott, 2003; Milliken 2001; Veltman, Cameron, & Stewart, 2002). In part, this is due to deinstitutionalization policies that have placed an emphasis on shorter lengths of stay in hospitals, greater restrictions on who can receive in-patient care and a lack of resources supporting individuals living with mental health issues in the community setting (Rose, Mallinson, & Gerson, 2006; Lauber et al., 2003; Fleury et al., 2008). As such, families and family caregivers are now providing services that once were provided by mental health institutions (Fleury et al., 2008).

The impacts on families and family caregivers from taking over caregiving responsibilities cover a wide scope of family life, including: work, leisure, income,

children, family health and relationships (i.e., friends, neighbours, extended family) (Maurin & Boyd, 1990; Baronet, 1999; Mental Health Commission of Canada, 2009). Families, as primary caregivers, help with medication, intervene and advocate for the individual to get treatment, provide assistance with activities of daily living, and provide emotional and practical support. This has led to, among other things, an increase in stress and burden on family members and caregivers and impacts on overall family health (Friedrich et al., 1999; Mental Health Commission of Canada, 2009).

Though many families are successful in coping with a family member with a mental health issue, still many families and caregivers have difficulties adjusting to the illness and suffer from burden, anxiety, and fear. Supporting families at the onset of the illness (early intervention) is important for overall health of the individual and the family. For example, the Mental Health Commission of Canada estimates that 70% of people living with mental health issues had their first symptoms or episodes while in their childhood or adolescence (Mental Health Commission of Canada, 2009). Additionally, families have also expressed that they feel unprepared for caregiving responsibilities (technically and emotionally). They reported a desire for information, access to professional advice, an ability to speak to someone about the loved one and recognition of their role. Families have also indicated they need: information and advice, affirmation, respect, a non-judgemental approach, a consistent one-on-one relationship with a health care provider, attentive communication and an individualized approach (Doornbos, 2002).

The context in which a caregiver may be providing care is often varied. The family member living with mental health issues may be living with the caregiver full-time or episodically. In other situations, caregivers provide supportive care to individuals living independently, in group homes or rooming houses, or to a family member who is homeless. Research has shown that there is a high degree of interaction between families and their family member living with mental health issues. For example, in the United States, well over 50 percent of people living with mental health issues have regular contact with family members (Ward-Griffin et al., 2005; Anthony, Cohen, & Farkas, 1990). Other research has shown that between 35 and 60 percent of people with severe mental illness live with their families (Ward-Griffin et al., 2005; National Institute of Mental Health, 1994). In the Canadian context, between 40 and 50 percent of people with schizophrenia live at home with their families (Ward-Griffin et al., 2005). This level of interconnectedness has important policy implications for both people with mental health issues and their family caregivers. Policies that affect one group will clearly have implications for the other, and vice versa.

Family caregivers and burden

The literature on families living with mental illness from the 1970s and earlier focused on the family's impact on the family member living with a mental illness (Ward-Griffin et al., 2005; Muhlbauer, 2002; Maurin & Boyd, 1990; Lefley, 1997; Baronet, 1999). Specifically, studies explored the role of families in creating, helping to cause or aggravating the mental illness of their family member (Lefley, 1997;

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Mulhbauer, 2008; Lidz, Cornelison, Fleck, & Terry, 1957). As a result, families were often to blame in these studies. Since then, the literature on family caregivers has shifted, primarily focusing on burden and in particular, the exploration of how caring for a family member living with a mental illness has resulted in a burden on families and caregivers (Baronet, 1999).

Objective and Subjective Burden

Researchers generally speak of burden in objective and subjective terms (Baronet, 1999; Ward-Griffin et al., 2005; Maurin & Boyd, 1990; Rose et al., 2006). The origins of the distinction can be traced to Hoenig and Hamilton's research on the impacts of people living with schizophrenia on the household (Hoenig & Hamilton, 1966; Maurin & Boyd, 1990; Loukissa, 1994; Baronet, 1999).

Objective burden is often referred to as the observable impact of the mental illness on the family, such as the financial loss of staying home from work to provide supportive care to a family member in relapse. Subjective burden is often referred to as the perceived or emotional impact of the mental illness on the family and the caregiver. Subjective burden can manifest itself as fear or guilt (Baronet, 1999; Ward-Griffin et al., 2005; Maurin & Boyd, 1990; Rose et al., 2006). Further, in a review of caregiver burden in mental health, Baronet (1999), describes objective burden as mostly being attributed to activities associated with the caregiving process rather than with behaviour resulting from the mental illness, whereas in contrast, subjective burden is mostly linked with behaviour stemming from the

illness itself (Baronet, 1999). The review further found that the highest rates of objective burden were associated with assisting family members with daily activities such as: financial aid, assistance with daily chores, and disturbances to the caregiver's personal life. The highest rates of subjective burden were associated with: concerns of safety, fear for the future, the level of dependency and need towards the caregiver, embarrassing actions as a result of the symptoms, and inter-relational conflict.

However, a more recent quantitative study of 30 family caregivers with a focus on burden, 'sense of mastery' over the illness, and context of caregiving, found that the highest rates of burden were associated with subjective burden, such as: worry about the future; guilt of not being able to do enough; feelings of being trapped; and being upset by changes in the patient (Rose et al., 2006). Areas where burden was least felt were objective types of burden and included: finances, missing work, and disruptions with friendships (Rose et al., 2006).

The emotional or psychological impact of burden can manifest itself as grief or a sense of loss. These types of burden can be thought of as 'tangible' in terms of affecting levels of ability to function or as 'symbolic' referring to expectations for the future (Rose, Mallinson, & Walton-Moss, 2004). This type of subjective burden often goes unrecognized and un-addressed by health care professionals (Rose et al., 2004).

A quantitative study of 186 family caregiver interviews found that subjective and objective burden were strongly correlated. What characterized the nature of

subjective burden was the type and intensity of the contact between the person with mental health issues and the family caregiver, and associated consequences (Lauber et al., 2003). For example, the result of subjective burden can be a loss in trust between the individual and the caregiver as a result of threats or violence.

Gender and Burden

Researchers have also discussed gender and the impacts of burden. Studies have shown that mothers tend to be the primary caregivers and have a greater investment in caregiving role (Saunders, 2003; Milliken, 2001; Cook, 1988). It has also been found that middle-aged and elderly women tend to be the primary caregivers (Chafetz & Barnes, 1989). For example, a 2004 Canadian study commissioned by the Women's Health Bureau and the Primary and Continuing Health Care Division of Canada found that approximately 70 percent of caregivers were women and that almost 50 percent of them were between the ages of 45 and 64 years (Andrews, MacLeod, Hendrickx, Chultem, & Kammermayer, 2004 in Government of Canada, 2006). Studies have also shown that because of this inequality, mothers have tended to show higher levels of emotional distress (e.g. anxiety, depression, and emotional drain) than their spouses (Saunders, 2003; Cook, 1988). Further, in a study involving 143 caregivers focusing on gender and caregiving found that daughters more often than sons assumed caregiver responsibilities for a parent with mental health issues (Coward & Dwyer, 1990).

In a qualitative study of 29 parent caregivers of family members with schizophrenia, Milliken (2001) found that mothers reduced their employment levels to give care, attended more peer group counselling sessions, took on blame for the illness and for exacerbating it, and felt more emotional stress of disenfranchisement. Similarly, in a quantitative study of 20 caregivers, the authors found that wives and mothers in particular experienced more blame and guilt for their relative's mental illness and for their disruptive behaviour than men (Veltman et al., 2002).

In another qualitative study exploring the caregiving experiences of fathers of family members with schizophrenia, Howard (1997) found significant differences in the caregiving roles along gender lines. Mothers tended to provide most of the primary caregiving, while fathers primarily contributed in indirect or secondary ways. An important aspect of burden for fathers was financial (medical and housing costs) and it was found that providing financial assistance was a form of coping by many of the participants (Howard, 1997).

Seeman (2009) found that this gender role of caregiving also extended across generational lines, where mother-caregivers not only cared for daughters with mental illness they also play a central role in raising their children as well. Grand parents are playing an important role in the caregiving process and according to U.S. Census data approximately 6.6 million or 9% of all children live with a grandparent (U.S. Census Bureau, 2009) and mental illness is a factor in grandparents taking on caregiving responsibilities (Seeman, 2009; McGowen, Ladd, & Strom, 2006). Multigenerational care has a greater impact on women than men as they tend to be

the primary caregivers; a role that impacts health and well-being and is often characterized by 'divided loyalties', burden, and reward of child rearing (Seeman, 2009). 'Divided loyalties' arise when grandmothers want their daughters to be well enough to take on greater responsibility in raising the children, but feel that their daughters are sometimes 'intruding' on what has become their new role; conflicts arise over how a child should be raised, their routine, discipline or education (Seeman, 2009; Goodman, 2003; Musil & Standing, 2005).

Seeman also found that though the role of care-giving mothers has changed to include a multigenerational caregiving component since deinstitutionalization, the biggest change has come in the perception of mothers. Once treated as responsible for the illness, they are now seen as playing an important role in supporting individuals with mental health issues in the community (Seeman, 2009). Seeman also points out that this change in perception has yet to be followed up with additional resources, influence on mental health policies or a change in 'recognition' by the legal system, mental health professionals, and their children for their caregiving role (Seeman, 2009).

Gaps in the research

Baronet (1999) and Maurin and Boyd (1990) have identified several gaps in the literature on family caregiver burden including: a lack of longitudinal studies, lack of heterogeneous studies, non-replicated findings, impact of the family environment on the experience of caregiver burden, and difficulties in the use of the terms

objective and subjective burden. Definitional issues arise when research uses self-reporting cases of objective burden; and where respondents themselves evaluate the adverse affects of the ill relative. In these situations, though the theoretical distinction may be clear, the distinction becomes less so because individuals exercise their personal judgment (subjectivity) to evaluate events (Baronet, 1999).

Similarly, Milliken and Northcott (2003) have made the critique that most research has been cross-sectional. They argue that the chronic nature of the illness and its un-linear pattern of recovery and relapse make longitudinal studies valuable to better understand burden and the actions of caregivers (Miliken & Northcott, 2003).

Further criticism of research on burden is that it has primarily been quantitative in nature (Ward-Griffin et al., 2005; Milliken, 2001; Lefley, 1997). Lefley identifies over 20 instruments that researchers have used to measure burden on families that do not effectively capture the "rage, frustration, pain, and grief" (Lefley 1997, p.212) of family members. A more recent study identifies over 200 instruments used to measure carer outcomes but "most lack data on reliability, validity or sensitivity" (Harvey et al. 2008; Harvey 2000). As a result, there are additional difficulties in comparing quantitative studies on caregiving because of the various instruments used to measure burden and the researchers' definition of the term. Though quantitative studies looking at burden have begun to consider the issues and factors involved in caregiving they fail to provide a voice to, or a perspective of, families in the caregiving process, or as Ward-Griffin states: "Although [quantitative] studies on caregiver burden move beyond the medicalization of mental illness, a deficit view of

family health is portrayed and lacks a family perspective of the caregiving process within mental illness." (Ward-Griffin et al., 2005, p.143).

For example, Harvey et al. (2008) in a review of instruments used to measure the outcomes for caregivers of people living with mental health issues, argue that the instruments used have not been developed to reflect the perspectives of family caregivers. This lack of inclusion has an impact on findings and could be attributed to the differences between quantitative and qualitative findings in this area. In particular, Harvey et al. (2008) point to the discrepancies between quantitative and qualitative research findings on the impacts of support groups for caregivers. Where qualitative research has shown the positive impacts of support groups for caregivers, quantitative research has shown mixed results (Harvey et al., 2008).

Mediating factors

Some of the mediating factors of burden for family caregivers are the presence of quality social support networks and the development of strong coping skills (Maurin & Boyd, 1990; Loukissa, 1995). Higher rates of burden were associated with families with poor coping skills and resources, and weak social support networks (Saunders, 2003; Magliano et al., 1996; Rose et al., 2002; Reinhard, 1994). Other factors that impact the severity of the burden felt by caregivers includes the severity or intensity of the symptoms (Rose et al., 2006). The Canadian Mental Health Association expands on the concept of the social support network (i.e., consumer groups and organizations, family & friends, mental health services, and

community services and groups) to include other elements of a 'resource base' which help to support the individual in the community and include: housing, work, education, and income. (Trainor et al., 2004). These elements of the resource base are important mediating factors for people living with mental health issues, their families, and caregivers.

Saunders (2003) in her review of literature of families living with schizophrenia found that low caregiver burden was associated with spousal involvement, participating with self-help groups, small social networks and overall satisfaction with support received from health care professionals (Saunders, 2003). Ferriter and Huband (2003) also found that family and self-help groups were the most beneficial in helping to lessen the impact of burden; the least helpful were professional sources of support (i.e. psychologists, social workers, psychiatrists).

Social stigma reinforces burden by cutting off links to social support networks (Rose et al., 2006; Jones, 2005). In one study by Rose et al. (1996), 56% of family caregivers expressed they were directly burdened by stigma. The authors further suggest that stigma outside of the immediate family (i.e. extended family and friends) becomes more acute as the symptoms of the illness increase and as the disruptive behaviour associated with the chronic nature of the illness affects personal interactions. Stigma constrains the ability of caregivers to reach out fearing a lack of understanding and negative reactions (Rose et al., 2002; Jones, 2005). Peer groups and self-help groups can play a central role in minimizing stigma by mediating the effects of isolation and alienation that family caregivers can feel from

their usual sources of support, such as extended family members or friends. Positive social supports further benefit family caregivers by helping them cope with the burdens of caregiving and overall family health (Saunders, 2003).

In a qualitative analysis of 76 interviews of family caregivers from National Alliance for the Mentally Ill (NAMI), Doornbos (2002) found that family caregivers, in speaking about the positive and negative aspects of the mental health care system, spoke to issues relating to the relationship between the family and the mental health system, services received, and issues relating to the broader social services system. Doornbos (2002) found that the non-supportive aspects of the mental health system included difficulties interacting with professionals within the system, system difficulties, and program funding. Parent caregivers interviewed expressed dissatisfaction with information obtained and frustration at being excluded from the planning of care. As a result, parent caregivers perceived that mental health professionals didn't recognize their role as caregivers, and had a negative impact on caregiver burden and overall family health. Issues with the system itself were related to problems of access and scope, programs and services. Services were only provided in situations of crisis and were often inadequate to meet their needs. What seemed to help family caregivers were situations where mental health workers took a proactive approach to help address the needs of families. Parent caregivers also felt that the mental health system wasn't as well funded as the rest of the health care system because of the lack of priority at the political level (Doornbos, 2002).

Similarly, a quantitative-qualitative study of 22 parent caregivers of a son with schizophrenia, found that help from professionals was the least supportive. Respondents indicated that a lack of information about their family member, the illness, medication, and what to expect were the most often cited complaints (Ferriter & Huband, 2003).

Family Perspectives on Caregiving

Researchers have begun more recently to better understand the perspectives of families and family caregivers. Studies have started to focus on perceptions of the experiences of living with the illness, the meaning caregivers attach to personal situations, the relationship of those meanings to coping responses, the chronic nature of the illness and how these change over time.

For example, Howard (1994) in a qualitative analysis of 19 in-depth interviews of mothers found that they underwent four learning stages in understanding how to live and provide supportive care to a child with schizophrenia including: perceiving a problem; searching for solutions; enduring the situation; and surviving the experience. Findings revealed an active caregiver coming to terms with the illness and defining their new role over time.

In addition, Rose et al. (2002), in a grounded theory study looking at family caregiver burden over 2 years, interviewed 29 participants from 17 families to understand family caregivers responses to their family member's mental illness over time. The uncertainty regarding the illness and the symptoms was the central

concern that families had. As a consequence, goals of family caregivers included: managing crises related to symptoms; containing and managing symptoms; and pursuing a normal lifestyle. Strategies included: dealing with their feelings of loss and acknowledging and supporting the strengths of their family member (Rose et al., 2002).

Further, Milliken and Northcott (2003), in a grounded theory study of caregiving for an individual living with schizophrenia, examined the parental identity in the caregiving process of 29 parents from 19 families. The authors found that parent caregivers faced challenges with the legal system, mental health professionals and also from the family member in assuming caregiving responsibilities. Parental family caregivers go through processes characterized by changing identities, which are closely linked with the 'trajectory of the illness'. Feelings of disenfranchisement follow periods of relapse and are associated with difficulties in dealing with the mental health system and their family member. Re-enfranchisement and the perception of emancipation from caregiving responsibilities involves redefining their own identity as parent-caregivers and are helped by associations with other parents (Miliken & Northcott, 2003).

Tweedell, Forchuk, Jewell, and Steinnagels (2004) in a qualitative study of nine families experiences of recovery or non-recovery from mental illness found that caregivers spoke of hope in terms of: the individual returning to their 'former selves'; being able to live and thrive independently; and cautious hope as their family had increased functionality and improved family relations.

Section Summary

As a result of policies of deinstitutionalization, families are now playing a bigger role in the caregiving process. Policy changes on how we provide services to people living with mental health issues have impacted every part of family life. Families and primary caregivers now carry out a multitude of tasks and functions that were once carried out by institutions. This greater role has led to increased burden and stress. Burden has been expressed both as the expression of the observable impacts of caregiving and the perceived or emotional impact of the illness. Burden can manifest itself as worry about the future, grief, sense of loss, guilt, and feelings of being trapped.

Stigma impacts the ability of family caregivers to cope with the burden they experience by cutting off links to social support networks. Burden is disproportionately felt by mothers as they tend to take on the responsibilities of being the primary caregiver, while fathers take on secondary roles. More recent research has begun to explore the longitudinal impacts of caregiving on family caregivers and in particular through their perspectives. The next section will further look at the perspectives of family caregivers with respect to housing.

2.5 Experiences and Perspectives of Family Caregivers on Housing

Why families' preferences matter in developing housing strategies

An important gap in the literature on family caregivers is their perspective on housing preferences for the individual living with a mental illness they care for (Browne & Hemsley, 2010; Ward-Griffin et al., 2005). This gap in the literature exists despite the central role of housing and family caregivers in the recovery process of individuals living with a mental illness. Housing is also a critical component of providing support for family caregivers. In a qualitative study by Doornbos (2002), family caregivers saw housing as an essential need in helping to support the family member in the community and to support themselves. As a result, access to decent and adequate housing can be a factor in mitigating family caregiver burden. Planners need to be intently aware of the interconnectedness of these factorss and how policies that affect one will affect the other.

Families differ from other stakeholders because of the intensely personal nature of the relationship with the individual living with a mental illness. They often share in the fear and uncertainty of relapses, and the relief and joy of recovery (Lefley, 2000). As a result, it is important, in order to develop effective housing policies and strategies, that families are involved in the processes that create new opportunities for their family members to access decent and affordable housing (Friedrich et al., 1999; Rogers, Danley, Anthony, Martin, & Walsh, 1994). Parents tend to be the primary caregiver even when the family member living with a mental illness does not live with the family. In that role, parents often provide supportive care, which

may include financial (Lefley 2000; Clark & Drake, 1994) and emotional support (Pickett-Schenk, Cook, Grey, & Butler, 2007; Clark and Drake, 1994), and may serve as the main advocates when the system is not responding to the needs of the individual living with mental illness (Lefley & Hatfield, 1999). Studies have shown that family burden may negatively impact the family member's ability to live independently in the community (Holley et al., 1998; Crotty & Kulys, 1986).

People living with severe mental illness frequently live at home rather than in other arrangements (Saunders, 2003; Kreig, 2003). Lefley has placed the figure of individuals living with mental illness living with family members at home around 50 percent (Lefley, 1996; 2000). A quantitative caregiver study in Canada identified that approximately 69% of caregivers lived with their family member with mental illness (Andrews et al. 2004). Further, studies have shown that between 50-90% of people with chronic mental health issues live with family members or have lived with family members after they have been released from hospital (Lauber et al., 2003). Further, in a 15-year longitudinal study of 134 people living with mental health issues in the U.K. found that more than 50% lived with their families, 23% lived in institutional settings, 19% lived on their own, and 2% were homeless (Browne & Hemsley, 2010; Brown & Birtwistle, 1998)

The numbers of people living with mental health issues living at home are also significant when looking at visible minority communities. For example, a study by Guarnaccia (1998) found that 75% of Hispanic Americans and close to 60% of

African Americans living with a mental health issue lived with their primary caregiver (Guarnaccia, 1998).

It is important for planners and policy makers to take into account the dynamics of particular subpopulations or newly arrived immigrants to understand the cultural perspectives at play regarding caring for someone living with a mental illness. For example, among newly arrived immigrants, higher levels of people are reported living with mental health issues living with their family and parents (Lefley, 2000). It is not clear, of course, whether this reflects cultural values or system functioning.

Family Caregiver Perspectives on Housing

Few studies exist that explore the perspectives of family caregivers on housing for people living with mental illness. For example, a quantitative study by Hatfield (1992) of 34 parents of family members living with mental illness identified that the primary factor triggering their family member with a mental illness to leave home and live somewhere else, was the availability of appropriate housing (Hatfield, 1992). Other factors that parents identified were excessive conflict with the person in the home, professional advice that the person should live elsewhere, and aging of parents and/or declining health (Hatfield, 1992).

A 1998 cross sectional study (Holley et al., 1998) of 183 patients with severe and persistent mental illness being considered for relocation from an institutional to a community setting found significant differences in the needs of patients and their families. The results showed that families often had differing points of view about

housing issues than both patients and clinical care providers. Issues discussed included proximity of relocation to their families, the amount of financial and emotional support required by families after relocation and the type of housing for relocation. The largest disconnect between family-patient pairs was around the type of housing for relocation, with 49 percent of patients preferring independent living as opposed to 10 percent for families (Holley et al., 1998).

Similarly, a 1999 cross sectional study (Friedrich et al., 1999) involving people with severe mental illness and their families identified that families tend to prefer housing with more supports. However, the study also identified that there was a strong correlation in housing preferences between family members and individuals with severe mental illness when current housing context is taken into account (Friedrich et al., 1999). Further research would be required to understand how past experiences and situational contexts have shaped perceptions on housing and supports.

A qualitative study by Ward-Griffin, Schofield, Vos, and Coatsworth-Pusposky (2005) identified that family caregivers often found themselves in a "vicious cycle" of care involving repeating the themes of witnessing inadequacies, working behind the scenes, and trying to create a better world (Ward-Griffin, et al., 2005). A central element in these themes was the importance of decent and adequate housing. Families often acted in response to inadequate housing situations by providing supports and advocacy, and working for 'change' within the mental health and housing system.

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Another qualitative study investigating family carers' perspectives on recovery of consumers, with a focus on housing needs found two major themes: 'safety and vulnerability' and 'stigma and the consequences of living with a mental illness' (Browne & Hemsley, 2010). In this study, the authors found that stigma was a considerable barrier to accessing decent and affordable housing in the rental accommodation market. Difficulties arose from dealing with landlords and the fear associated with revealing mental illness, losing accommodations when their loved ones had relapses, the lack of adequate support services provided in the community and the instability of rental accommodations due to high rents (Browne & Hemsley, 2010). The study also found that carers' visions for housing for someone leaving the hospital setting included: safety as a 'cornerstone of rehabilitative housing', supportive services to regain life skills, their own space (i.e. separate flats or rooms), flexibility and choice in accommodation (Browne & Hemsley, 2010).

As has been discussed, having access to decent and adequate housing is central to people with mental health issues living independently in the community. Part of living independently in the community means having supportive relationships. A study by Browne and Courtney (2007) examined the importance of housing in helping to strengthen supportive relationships for people with schizophrenia. The authors found that maintaining quality housing was essential in supporting social relationships and vice versa. Quality housing and a strong social network were also shown to reduce hospitalization. As a result, the authors point to a need to better understand the subjective experiences of people living with the mental illness and

their families in relation to housing and support networks (Browne and Courtney, 2007).

Section Summary

Processes of deinstitutionalization across North American and Europe have transformed the way we care for people living with mental health issues. The impacts of this major shift in mental health policy has had tremendous effects on people living with mental health issues, which include a transfer of institutional type care into the community setting, homelessness, and increased criminalization. These policies have also impacted their families and caregivers as they play a critical role in providing supportive care and promoting recovery. Unfortunately families and family caregivers have largely been ignored and left out of the discourse on issues that directly affect them and their families. This marginalization has negatively impacted them and the overall health of the family (Ward-Griffin et al., 2005).

Research on family members has largely been quantitative and has dealt with burden and the impacts of burden on families. Qualitative research that explores how family caregivers perceive the housing system and the nature of the supports available to them and the individual living with a mental health issue is needed. To address these gaps in the literature, this thesis will explore the perspectives of family caregivers regarding issues of caregiving, supports, and housing. The study will explore the perspectives of family caregivers to provide a deeper understanding of how caregivers interact within the mental health and housing system.

Research that takes into account past experiences of housing will provide a deeper understanding of the mediating factors that influence families' perceptions and actions. Housing is a key determinant of health and a major policy area critical to understanding the preferences of people living with mental health issues and their families (Friedrich et al., 1999; Ward-Griffin et al., 2005). For policy analysts and planners wishing to establish housing policies that work for people living with mental health issues and their families, requires broadening the consultative input from health care and social service professionals, to include those who are directly impacted by policy decisions.

3.0 Methodology

3.1 Introduction

The primary method of research for this thesis is the analysis of nine family caregiver interviews with people who provide supportive care to a member of their family living with mental health issues in Winnipeg. The source of the interviews was a joint academic/community research project conducted in 2008 (Skelton & Mahé, 2009). This project was part of a larger CURA grant administered by the Canadian Centre for Policy Alternatives. This research project undertakes a new analysis of the nine family member caretaker interviews conducted by the present author or under his supervision. The interviews were semi-structured and averaged 60 minutes in length. All of the participants were women and all were the primary caregiver of an adult family member with a chronic mental health issue (e.g., psychotic disorders, mood disorders or anxiety disorders). Of the nine participants in this study, eight of them were mothers caring for their adult child; the other participant cared for her mother. All of the participants lived with their family member at the onset of the mental illness, however at the time of the interviews, none of the participants lived with their family member.

The method of analysis for this research project is informed by critical discourse analysis (CDA). CDA, with its focus on language, discourse and power provides a complementary approach to the collaborative planning theoretical framework for the analysis of the interview texts.

3.2 Critical Discourse Analysis

Critical Discourse Analysis provides a framework for understanding language and power and how they are used to shape discourse, perceptions and social action. It also provides an approach and a tool to analyze public modes of discourse, such as texts, policy documents, and interviews (Caldas-Coulthard, 1996). The purpose of CDA is to unmask the underpinning "… structural relationships of dominance, discrimination, power and control as manifested in language" (Wodak, 2002, p. 11).

In this light, CDA is of particular importance for planners. Planners don't create plans in isolation; they are active participants in a public discourse in which they mediate between groups, communicate, share knowledge, and advocate on behalf of particular section of society. Discourse plays an important function within those various planning roles. Of paramount concern to planners is to understand not only how discourse represents people and groups within society, but also how it shapes our perceptions, actions and relations with these groups and individuals (Fairclough, 1992; Sandercock, 1998). Additionally, planners today require a keen understanding of multiple publics, social interactions and differences; of making the invisible visible, or as Leoni Sandercock also states, "[a need for] expanding the language of planning" (Sandercock, 1998, p.207).

CDA research can assist in supporting processes of change by exposing power imbalances and revealing experiences and perspectives of individuals being planned for and not with. The literature review above identified that family caregivers' qualitative experiences and perspectives have not been fully explored, in particular

regarding housing. Also, the review showed that family caregivers have been left out of the discourse in shaping how mental health and housing systems would relate to both people living with mental health issues and their family caregivers. Yauk (2008) argues that CDA can be used to reveal how language and power can be used as a tool to suppress and marginalize, but that it can also be used for empowerment. This is of particular importance in mental health research because of the mechanisms through which fear and stigma can shape the way we perceive mental health issues, social actions and policies.

Roots of CDA

CDA has roots in linguistics, literary criticism, and the social sciences (Caldas-Coulthard, 1996). From the linguistic perspective, CDA draws a lot of its theoretical foundation from semiotics, a term associated with de Saussure, which is concerned with the analysis of symbols and meanings within society, with a particular focus on language (Caldas-Coulthard, 1996). In particular, CDA has been influenced from the pragmatic branch of semiotics, which is the analysis of language, meaning and the intersection with the individual (Burr, 2003). In other words, the concern is with how meaning is constructed within society through language and social interactions. This is in sharp distinction from the other branches of semiotics, that focus on other aspects of language, such as syntax, which concerns itself with the grammatical form.

Structuralism and post-structuralism, which owe their formation in linguistics to de Saussure, are concerned with exposing the underlying structures of text (Hanfling, 2002). In structuralism, words have two parts to them; there is the 'signifier' and 'signified'. 'Signifier' is the term used to for the object or the sign, for example *horse* or *law*. 'Signified' refers to the concept of *horse* or *law* and the meaning associated with that word. For structuralists, the link between the object and the concept is arbitrary, meaning it is the processes in social interactions and culture that construct concepts (signified) and associate words (signifier) or categories to them (Hanfling, 2002). As Burr explains, "Language does not reflect a pre-existing social reality, but constitutes and brings a framework to that reality for us. It is the structure of language, the system of signifiers and signifieds and their meanings as constituted in the differences between them, that carves up our conceptual space for us" (Burr, 2003, p.52). *Differences* play an important role in the meaning of words for structuralists, as concepts are only understood in relation to other words.

Post-structuralism and structuralism share two principal ideas. First is that social interactions and discourse construct individuals, their perceptions and their actions. Second is that they deny the 'essentialist nature' of the individual; that a peoples' experiences, thoughts and emotions come from within (Burr, 2003). For structuralists, the focus of study should be the social sphere and not the individual. Post structuralism builds upon structuralism by answering questions not addressed in structuralism. In particular, structuralism does not address how the meaning of words changes over time or how words can carry various meanings depending on the context of: who said them; when they were said; and why (Burr, 2003). The

point of departure from structuralism, for post-structuralists, is structuralism's position on the stability of the meaning of words. As the meaning changes, the social processes (discourse) that initiate this change are characterized by instability, argument and struggle, or as Burr describes, "… with the post-structuralist view of language we are drawn into a view of talk, writing, and social encounters as sites of struggle and conflict, where power relations are acted out and contested" (Burr 2003, p.55).

CDA builds on these concepts, by focusing on the action or 'performative' aspect of language. Analyzing the processes of discourse brings to the fore the direct links between language and power, more precisely, how people or groups react to or move within these discourse systems. As Blommaert states, CDA "… identifies the multiple ways in which individuals move through such institutionalized discursive regimes, constructing selves, social categories, and social realities" (Blommaert and Bulcaen 2000, p.449).

In process and intent CDA is explicitly political in its approach to research. As Caldas-Coulthard states regarding the nature of CDA: "… its practitioners [are] acting upon the world in order to transform it and thereby help create a world where people are not discriminated against because of sex, colour, creed, age or social class" (Caldas-Coulthard, 1996, p.i). In this respect, it can be seen as part of the critical social sciences, where research takes an activist position. As Harding (1986) argues, "it challenges the belief that science must be protected from politics. It argues that some politics – the politics for emancipatory social change – can

increase the objectivity of science" (Harding, 1986 in Neuman, 1997, p.79). Additionally, both critical discourse analysis and the critical social sciences can trace their roots of influence to the critical theorists of the Frankfurt School during the 1930s (Neuman, 1997; Caldas-Coulthard, 1996).

CDA also has deep roots in social constructivism, which takes the position that social inquiry needs to question our general understanding of the world and what we know to be true. It refutes the positivistic approach that an objective, unbiased truth is out there in the world to be discovered (Neuman, 1997; Burr, 2003). Knowledge, and the categories by which we view and understand the world, are socially constructed. This process is created through social interactions, discourse and ultimately language. In this sense, language is more than a vessel for our thoughts and emotions; it has what Burr refers to as a 'performative role' (Burr, 2003). Language becomes an active player in shaping social interactions and so has implications for power dynamics and control.

Foucault argued that the way we speak about people in society has implications for how we treat them and what they are permitted to do. He used the example of mental illness and how our discourse on mental illness within society has led to certain power relations and aspects of control. This concept of power dynamics is epitomized by the power relations between psychiatrists and other medical professionals, and people living with mental illness and the control that is exerted over certain parts of their lives (Burr, 2003; Foucault 1961).

The influence of culture and time also plays an important part in this process because discourses – past and present – evolve over time and impact the way we construct our reality (Burr, 2003). For example, the perceptions and thus attitudes and actions towards people living with mental health issues are not uniform across cultures or within cultures over time. This process of language and social change is of key concern for researchers in relation both to the collaborative planner's theoretical framework approach and to CDA methods.

3.3 Applying the Methodology

CDA does not provide a uniform set of methods for the analysis of texts; rather researchers who use CDA refer to 'approaches' to analyze text (Parker, 1999; Fairclough, 1995). This lack of a coherent (or specific) methodology for the analysis of text is generally perceived as the greatest critique of CDA (Parker, 1999; Fairclough, 1995). Consequently, I incorporated some of the methods illustrated by Neuman and Strauss, which include open coding, axial coding and selective coding. Through successive readings of the interview transcripts, I have analysed words, phrases, sentences and whole texts in relation to the larger system of meaning to question their contradictions, constructions, and performative role (Parker, 1999). Looking for contradictions or differences within texts, the researcher seeks to determine different meanings ascribed to words or themes in order to understand the different representations of the world or events (Parker, 1999). Identifying differences in text can also help in understanding which dominant cultural 'myths' are present and how they help to shape perceptions and actions. Such a research

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process is recognized as a useful tool for researchers as a means to understand how meaning is socially constructed and used by individuals interviewed (Neuman 2000). The performative role, or practice, refers to discovering what are some of the outcomes of the contradictions (or differences) in the systems of meaning (Parker, 1999). It is in this section that a deeper analysis is done to uncover power relations and dynamics and how individuals navigate systems of meaning and how they might struggle to create their own meaning (Parker, 1999).

DATA

In qualitative research, data comes in the form of written texts, audio recordings, and images (Neuman, 2000). Data for this study are the written texts of the interviews conducted as part of the joint academic/community research project mentioned above. Having been a part of the original study that produced the data and having been the lead interviewer in all of the interviews, I have an intimate knowledge of the context and nuances that are a part of every semi-structured interview. This understanding of the data provides me with another perspective that is not always afforded to researchers analyzing recorded text. The importance of context and data is described by Neuman (2000), who states: "data are in the form of words, which are relatively imprecise, diffuse, and context-based, and can have more than one meaning" (Neuman, 2000, p.419). Similarly, Mason (2002) argues that text-based data from semi-structured interviews can be difficult to organize, lack coherence or have a straightforward narrative. Because I have

conducted the interviews, any difficulty in interpreting will be mitigated by my experience with the interviews and the context.

CODING

Coding is the initial step in the process of analyzing data. It is a process by which the data is organized, placed into categories and themes and then analyzed (Strauss, 1987; Neuman, 2000). Neuman (2000) describes coding as: "two simultaneous activities: mechanical data reduction and analytic categorization of data into themes." (p.421). In other words, it allows the researcher to organize the data in such a way that it is more manageable to use. In particular, categorizing data into themes allows the researcher to access and retrieve the data quickly. The texts were read using three different lenses identified above: open coding, axial coding and selective coding, which build upon each other in the analytic process.

OPEN CODING

Open coding provides for an understanding of the content and scope of the data and provides the researcher with a 'familiarity' with the data set as a whole. The open coding stage of analyzing the data included reading over the text from the recorded interviews while listening to the audio recordings of the interviews. This step of listening to the audio recordings, while simultaneously reading the transcripts of the interviews, helped me to re-immerse myself into the data. 'Reading' the material

in this way triggered vivid memories of when I conducted the interviews, and helped me to regain a sense of the participants and the way in which they responded to questions. In this first 'pass' through the data, I created a profile chart of each participant with the intent of outlining what was supportive/unsupportive in allowing them to provide supportive care to their family member, the housing history (by type of housing) of their family member and their general thoughts on housing preferences. The goal was to use the descriptive profile chart as a means of supporting subsequent readings of the data; to help manage the large amount of data collected; to have a quick reference guide that could help understand the completeness of the data for each participant; and to help the process of organizing ideas and codes.

I conducted two more readings of the data as part of the open coding process while "looking for critical terms, key events, or themes" (Neuman, 2000, p.421). Themes and issues raised by the literature review were also considered and kept at the forefront of my mind during the open coding process. As part of this step, notes were taken down and registered along with the code given. Attention was also explicitly given towards keeping an 'open mind' towards potential new ideas and codes. These initial codes (see Table 1 below) were my first attempt at beginning to put order to the data. The goal of this process was to identify the emerging themes within the data and to begin the process of further analysis by creating a list of broad themes that would be critically assessed, compared, modified, added to and removed (Neuman, 2000). The number of passes through the data during the open

coding stage was determined by the level of saturation with the data and themes that emerged.

Table 1 - Initial codes

1. Burden
2. Stigma
3. Family
4. Illness
5. Independence
6. Normalcy
7. Advocacy
8. Financial Issues
9. Supports
10. Systemic Gaps
11. Isolation
12. Identity
13. Housing preferences
14. Housing dislikes
15. Challenges
16. Education
17. Enabling
18. Supporting
19. Intervene
20. Support groups

AXIAL CODING

Axial coding is a process by which codes identified within the open coding stage are scrutinized and analyzed in relation to other concepts, themes and ideas. As Strauss states, "it consists of intense analysis done around one category at a time […] and results in cumulative knowledge about relationships between that category and other categories and subcategories" (Strauss, 1987, p.32). During the axial coding stage I reviewed the existing codes from Table 1 above and made modifications where needed based on the data from the interviews and themes from the

literature. As a result, codes at this stage were added, modified or eliminated. It was also at this stage in the process of analysing the data that connections between themes were made (Neuman, 2000). As Neuman (2000) describes, "the researcher asks about causes and consequences, conditions and interactions, strategies and processes and looks for categories or concepts to cluster together" (Neuman, 2000, p.423). It is a process that involves both deductive and inductive reasoning, which, as part of the output of this stage, produces a set of "core" themes, and categories that will be the primary subject of analysis. The axial codes are discussed in Chapter four.

SELECTIVE CODING

The last stage of reading through the data consisted of selective coding, a thorough analysis of codes, data, and concepts identified in previous stages and how they relate to the core themes that were developed (Strauss, 1987). It is also in this stage that illustrations of data are selected to represent concepts and ideas from the core themes, or as Neuman (2000) argues, "researchers look selectively for cases that illustrate themes and make comparisons and contrasts" (Neuman, 2000, p.423). As part of this process I developed a spreadsheet with the various codes, themes and categories derived from the open and axial coding stages. Selective readings of the data were then undertaken through the lens of these core concepts.

It is important to note that the coding process was not as categorical in its delineation of tasks as may have been described to date. Overlap between the

coding phases occurred and helped to strengthen the overall coding process and data analysis. For example, selective coding did not play a primary role in the early stages of reading through the data. Its importance as a step in the process increased as concepts and themes were developed and required further analysis.

MEMO WRITING

Memo writing was an important tool in all of phases of the coding process and data analysis. In addition to the participant profile chart I created in the open coding process, additional notes were written into the margins of the interview transcript documents. These margin notes on specific codes and chunks of data were then further developed to articulate ideas, themes, sub-themes, concepts and categories in a separate Word document. Memos were linked back to the data (through notations) to provide illustrations and to ensure that the ideas and concepts developed were grounded in the data. All memos on themes and sub categories were kept in one Word document in order to allow for easy access to ideas, but to also facilitate the reorganization and sorting of themes and concepts. Memo writing is an important tool for supplementing the coding process and generation of ideas and concepts as Neuman (2000) argues: "The analytic memo forges a link between the concrete data or raw evidence and more abstract, researcher's reflections on and thinking about the data and coding" (Neuman, 2000, p.425). The memos written in this research project were refined and developed with each subsequent reading of the data in order to build arguments and concepts.

4.0 Analysis of Interviews

This chapter will discuss the results of the data analysis and review themes identified in the interview texts.

4.1 Basic Findings

The findings are intended to help provide an insight into the experiences of family caregivers in providing supportive care to a family member living with a mental health issue within their local context. Themes that emerged from the data include: Fighting for Normalcy, Responding to Burden and Stigma, and Centrality of Housing. The findings from this data cannot be extrapolated to provide generalized impressions of the perceptions of all family caregivers but are intended to provide a contextualization of how local policies affect the world in which this group of participants act.

Early readings of the family member caregiver interviews revealed a complex set of relationships between codes, as listed in Table 1 – Initial Codes. Further readings led to a constructed narrative that would make a coherent explanation of the relationship between codes. The themes discussed in this chapter are the core themes that emerged through the axial coding stage of the data analysis process. Table 2 – Axial Codes show the linkages between themes and how the initial codes relate to the core themes discussed.

Table 2 – Axial Codes

1. Fighting For Normalcy

2. Responding to Burden and Stigma

3. Centrality of Housing

The major themes that emerged as part of the interview data are strongly interrelated. The concept of fighting for normalcy underpins and links the core themes together and shows these family caregiver participants as active agents trying to shape their own circumstances and those of their family member. Stigma, burden, and housing were critical areas where this fight for normalcy played out.

Burden and Stigma can have debilitating effects on caregivers, their families and on overall family health. Family caregiver participants actively resisted and sought to mitigate these impacts on all areas of family life (e.g., through advocacy and working behind the scenes and joining/creating support groups). Their resistance is reflected in their attempts at reclaiming a sense of normalcy from the burdens they face in the caregiving process, whether from the effects of the illness itself, the structural barriers imposed by the health and housing system or the pressures of stigma from family, friends and society.

Housing was understood as an important tool for realizing the goals of independence and normalcy. Consequently, housing can be perceived as a critical component of the resource base not only for the individual living with mental health issues but for the family caregiver participants as well.

As a result, family caregivers also experienced marginalization within the housing market through stigma and structural barriers (e.g., location of housing, types of housing available, and availability/quality of supports). This marginalization was characterized by: a loss of independence; of choice in where to live and with whom, which meant a loss of connection to their community; a decrease in health outcomes for both the family member and the individual with mental health issues; loss of social integration and safety; an increased housing insecurity; and an increase in caregiver burden.

4.2 Fighting for Normalcy

Fighting for normalcy was a core theme that linked participants together, in part through their shared experience of burden and stigma. For many participants normalcy was a goal to be strived for, both for the individual with mental health issues as well as for the entire family. Normalcy was important for them as a means to get back to the life trajectory before the illness. There was realization that this trajectory wouldn't be the same but that certain elements of it would be within reach for their family member and themselves and that they should be realised. Independence was a phenomenon associated with fighting for normalcy. That meant having a strong resource base for their family member that encouraged them to be socially engaged, have employment, contribute positively to society and have 'normal' housing. It also meant having the opportunity to pursue life goals that everyone else has.

Fighting for normalcy for family caregivers not only meant addressing and overcoming external structural barriers, but also included overcoming internalized understandings of societal discourse on familial roles, identity, normality, independence, and mental health.

Changing Minds or Redefining Normalcy

Pursuing a 'normal' lifestyle meant that family caregivers had to change their own minds and perceptions about mental illness, normalcy and family roles. A participant described her struggle to find a new sense of normalcy and redefinition of their familial roles:

> (F1) I had to adapt the way that I think about being a child, being somebody's child. I had to realize that life isn't always the way that you want it to be. There are many occasions where I've been able to have a choice in life, to be optimistic and keep going. There is a choice you know; we don't have to be the product of our experiences. You can choose; you have the power to do that.

While support groups were important components of coping with stress and burden, they also were involved in the struggle for normalcy. A participant spoke of the role of support groups in providing the necessary tools to allow them to adapt to their circumstances and change their perceptions of what it is to live with a mental illness:

> (F4) I had an attitude change… recovery is a process that is one stepping-stone at a time. We need short term and long-term goals and we are going to accept the fact this is going to take a lifetime of recovery.

For most participants, there was recognition that fostering independence and normality for their family member required a re-assessment of how they provided supportive care. Some examples:

> (F6) The major adjustment I made was moving on with my life so that my son could move on with his. It was probably the greatest thing to do [but] it was also a really hard thing to do.

> (F2) I think I'm learning and I think I'm learning that I can't do everything for my son, but I sure as hell can appreciate what he's done for himself and I will let him know that.

Changing the system

These participants were not passive actors or victims of the caregiving situation they were in; they reacted, got involved and tried to shape the system they were "thrown into". The latter term signifies that their participation in this system was not voluntary or foreseen. Their involvement was sudden and unexpected. It jarred their sense of the world. They moved from certainty to uncertainty. Most participants began by seeking information and support, then moved to advocate for what they felt was needed based on their experiences as primary caregivers.

Many participants joined parent groups and began to get involved to try to change the system. For most participants housing and responsive support services were an important component of independence. For example:

> (F6) I joined [group] in 2002. It was my way to put input into the system that sucked. [Affecting] policy can affect more people than building a building. A building is not the answer. Changing policy is what is needed. Do you know how many people in Winnipeg have housing issues?

Many family members felt the need to work behind the scenes to fill the gaps in the system and to make it more responsive to the needs of caregivers. Some examples:

> (F8) [Our role] is to let people know what is working and what is not working. To ask questions, to advocate for their family member. When things weren't working we contacted a lot of people. Family groups are actually what pressured the government to start the EPPIS [Early Psychosis Prevention and Intervention Services] program. The families are in the situation and they know what is needed.

> (F9) I don't know that mental illness is on the radar screen for the provinces and the federal government. I would hate to see what would happen if we didn't push as hard as we did.

Fostering independence

All participants worked towards creating conditions where their family member could live an independent and normal life. What parents did and how they reacted depended on the unique circumstances of their situation. Elements of the resource base were family and friends, education, housing, and work.

Many participants encouraged independence and tried to minimize the stigma associated with having a mental illness by encouraging and supporting their family member to find and retain employment instead of relying on social assistance. A participant described the structural difficulties encountered in fostering that independence:

> (F9) You just want some supports for someone who is working. You either work or you go on social assistance. I think we should be encouraging people to work as much as they can, but to also recognize that some people need additional support so that they don't end up in the hospital. (p.3)

For some participants supporting independence meant working behind the scenes trying to ensure their family members had the same access to the same opportunities as any other member of society. For example, a participant described working in this way to support their family member, who wouldn't self-declare having a mental health issue out of fear of being stigmatized:

> (F9) When he went to Red River he didn't want to declare having a mental illness. He didn't want the stigma. I would talk to his teachers about maybe some of the work not being on time. Advocating for a 21 year old is a little different and awkward than advocating for a high schooler. A lot of it was through the back door.

As a result, family caregiver participants were not passive recipients of the burden associated with caregiving processes, stigma and the structural limitations of the health and housing social systems. They responded by fostering independence, working behind the scenes, advocating, changing their own perceptions, and changing the system.

4.3 Responding to Burden and Stigma

Many of the participants spoke about wanting to be a strong component of their family member's resource base; a positive mediating factor helping their family member lead an independent and 'normal' life. Not knowing how and when to provide appropriate supportive care to their family member was often a source of burden for participants. It often manifested itself in worry, frustration, grief, and sense of loss. A lack of timely and appropriate support from social systems, insecure

or inappropriate housing, manifestations of the illness, drug use and relapses intensified this sense of burden. Family caregiver participants were actively engaged supporting their family members by providing supports such as: emotional care, assisting with daily skills (cooking, cleaning, transportation etc.), and financial resources.

Some participants spoke of the difficulties of not knowing how to intervene and provide appropriate supports for their family member. An example:

> (F4) Mothers do as well as their children do. If you're a parent, if they have a good week, I have a good week. I try not to get on the same roller coaster ride as he does. I try to step back and let him go for a ride once in a while and eventually he gets off and he comes down.

Other family caregivers expressed their frustration at the inability of social systems to provide timely and appropriate supports to people living with mental health issues and their family caregivers:

> (F2) There's a lot of support needed for us too in how to manage and access the proper treatment, how to provide for them so they're not let to delve into the greater world of drugs and living on the street.

For another participant, their family member's self-medication intensified the burden she and her family experienced in providing supportive care:

> (F8) It's that balancing act between care, love, support, with enabling and increasing dependence on us [on the other].

Having access to timely supports for parents, which included emotional support, education, knowledge and expertise, helped to ease the sense of caregiver burden. As one participant described:

> (F9) EPPIS [Early Psychosis Prevention and Intervention Services] was very helpful. They would encourage him and also to talk to me about how to intervene. That's one of the hardest things as a parent of a young adult, [knowing] when to step in and help and when to stand back and let him help himself.

Caregiver burden impacted the overall health of many of the participants and that of their families. Not having appropriate access to resources and supports from social systems contributed to this deterioration. Some examples:

> (F8) Family stress. It becomes so chronic you don't even notice it. Both my husband and I were treated for depression from the long-standing stress. It's kind of like a cloud.

> (F3) I'm burnt out. I've been retired now for seven years and I'm totally exhausted and burnt out right now and I shouldn't be. It's energy draining and we're both burnt out from my daughter's experience. So when I do have energy I seem to be getting sick and now my husband is having heart problems. I don't know what will happen to my daughter if my husband and I died today.

Caregiver burden was also linked to their perception of their family member's level of independence. This assessment of independence was particularly associated with their housing situation and the presence of social supports outside the family unit:

> (F5) I guess I find it draining sometimes that I am his main social support and that it's not that I don't care about him, it's simply because I'm almost 62 and I'm looking at him 35 years old and I know that at some point I would like to spend more time with grandchildren and to be able to have that feeling of freedom.

Burden and Siblings

Trying to keep a sense of normalcy within the family unit was an important coping mechanism for many of the participants. A participant described the importance of actively trying to work towards regaining a sense of normalcy for the other siblings:

> (F8) One of the difficulties we faced was trying to maintain a normal family life [for the whole family]. I know your brother is smoking dope and punching holes in the wall, but I need you to do your homework.

Stigma and Support Networks

Stigma was a reoccurring theme that emerged from the interviews. Stigma appeared as a multifaceted phenomenon that affected many aspects of the lives of the family caregivers. It was strongly related to burden, access to support services, and family and friends. Stigma is a barrier for participants; a negative factor that can have a considerable impact on whether nor not an element of the resource base for caregivers and their family members will be supportive. This not only has a direct impact on whether or not an individual can live independently in the community successfully, it also directly affects the level of burden experienced by family caregivers.

Stigma inhibited family caregivers from inquiring about and getting access to the necessary supports and in particular at the onset of the first mental health episode. As a result, it impacted how caregivers managed burden and access to proper treatments. A participant described how stigma impacted their world:

> (F2) I'm very proud of him. It's something that I couldn't say years ago. I was afraid to tell the neighbours, afraid to tell many, many people. Who did I tell? Who could I ask? Who could I talk to?

Many participants expressed a need to overcome their own perceptions and attitudes vis-à-vis mental illness and responded by educating themselves and getting the supports they needed:

> (F9) The number one thing [we did] was getting educated. Number two, getting the support group to take care of us and deal with our own fears, our own sense of loss and having to deal with my own biases about mental health.

> (F6) In the beginning you just don't know and you think everything is the illness... sometimes its just bad behaviour. She [case manager] was very helpful in getting us over the stigma. He was just a person with an illness.

Friends and family can be important parts of the resource base that help to mediate against the effects of stigma and the burden of caring for a family member with a mental illness. However family and friends can also be factors that are not supportive to the caregiver. Some examples:

> (F3) I wish I had people for support but I don't have it. I think I lost my friends along the way because this [mental illness] is all I talk about. This has become my life and I keep saying to my husband, so when is this going to end, when do I stop worrying.

> (F4) We inherited a shame-based attitude from my family. In my family there's such a tremendous amount of ignorance around the illness. They don't understand what it is; they don't want to understand. They have premature attitudes and in my family I'm sorry to say it's ignorance.

Stigma can be challenging within the family, as it isn't always overt, but there can be subtle expressions of discrimination, as one participant described:

(F9) It wasn't overt. You know people are uncomfortable. My family as I said, I have lawyers and physicians in the family, but it doesn't matter how educated you are. I have a 22-year-old daughter and a 25-year-old son. They will ask my daughter to come over and not my son. It's a little hurtful.

A participant spoke of the difficulty they experienced encouraging their family to live a normal life, but felt that stigma undermined these efforts by limiting their social independence:

(F5) Even though he's moved back to an area where he used to have friends growing up, you don't have friends again in the same way as an adult that you made as a child. Now he's completely demonstrated his psychosis at work [...] and they support him but they're not going to invite him out for a beer. So he's limited there.

Coping with Burden and Stigma

Participants responded to the burden of caregiving and the stigma in many of the same ways. Formal and informal support groups were important places for participants to deal with their burden, to cope and to learn how to cope. Many participants also expressed the importance of support groups in playing a positive mediating factor in alleviating burden resulting from stigma. Some examples:

(F6) It was hard until we found a support group to go to so that I could learn more about it. That's where I learnt everything. There were other parents I could talk to. It was the best thing for me because we really felt isolated.

(F4) [Support group] provided a supportive environment for crisis, because you are in crisis when you are at the first onset, the first psychosis. Everybody goes through crisis, family members, everybody. When you share grief together [...] you never lose the feeling of friendship with these people.

> (F2) if you start a group and you build up towards the greater understanding, it's the willingness to share and meet the challenge because when you share a burden, sometimes you can also share the positive results.

In some instances support groups were not a positive mediating factor. One participant in particular expressed frustration they felt at being discriminated against for being aboriginal:

> (F3) I needed peer counselling from a mother or a father that had a son or a daughter with schizophrenia to take up some points on how they help themselves and how they coped. But each member that I called to go for coffee … oh I'm busy, so I haven't connected with one person.

Families could also be important factors in alleviating the sense of burden experienced by family caregivers, as a participant described:

> (F9) I would hate to think that there are people who have this illness and have a destructive family. The effort we put into supporting him and into supporting ourselves and keeping each other sane.

Family caregivers had different strategies for managing, coping or responding to the stigma they experienced while providing supportive care. For example:

> (F4) We taught him to develop almost cast iron walls, to be very careful on what you say, who you approach with your illness, what you share. He's got a protective barrier and we taught him that.

A family caregiver described her role as being a proactive advocate against stigma:

> (F9) The advocacy thing is something we understand better than anybody else. That's what I try to do. I want to take away some of that stigma.

Burden from the caregiving process was an important factor for all participants in that it impacted their ability of being a positive component of their family member's resource base, helping them to achieve their goals of normalcy. Mediating factors such as support services, social networks and housing played an important role in either intensifying that sense of burden to mitigating its effects. Stigma is also an important factor that can disrupt a caregiver's resource base. The ability to cope with burden and stigma was important to the overall health of the caregiver, the family and to the ability of the caregiver to continue to be a supportive member of the resource base of the individual living with mental health issues.

4.4 Centrality of Housing

Housing was described as both a positive and negative mediating factor for family caregivers. When their family member with mental health issues is not in appropriate housing, housing ceases to become a mitigating factor against the effects of burden and housing itself becomes a source of burden for the primary caregiver and the entire family. Appropriate housing was seen by family members as an important normalizing factor with strong links to social integration, employment, and the pursuit of life goals. As a result, family members were active in supporting their family member to live independently in community, to get access to housing and to advocate on their behalf.

The struggles family caregivers faced in the housing sector included: fostering

independence, finding appropriate housing to meet the needs of their family

member; knowing where and how to access housing; finding affordable and quality

housing; encountering stigma in the private housing market; a lack of publicly or

privately provided housing options; and having access to appropriate support

services.

Independence through Housing

It was the expressed goal and hope of all participants that their family members live

an independent and normal life. Independent housing was perceived as an integral

component to the realization of that goal. A participant described the long trajectory

to independent housing this way:

> (F4) For my son, he lived at home for two years until we got him into a
> group home. Independent housing took 10 years. If we're patient it does
> happen.

Some participants described the difficulties of encouraging a healthy, normal

lifestyle through independent housing in the face of isolation and stigma within

society:

> (F8) Watching your son not being able to do the things his friends are
> doing, that's sadness. Especially knowing that they have potential. He's
> made the most progress in the last year since he's moved out. By making
> him move out, kind of forced him to… he really didn't want to move out,
> wasn't easy to do. He's actually trying to pursue things [now].

> (F9) He moved out last summer and began working. To normalize things.
> A young guy who is 24, who is working, should be living on his own […]
> he doesn't initiate a lot on his own, so sometimes he lives like a hermit.
> He has old school friends. He has had some that have been loyal and

there are some that have carried on with their own life and can't be bothered as much. There is a little discomfort there. But it's about encouraging him to get out there and live a healthy lifestyle.

Fostering Independence

All participants had their family member living at home with them at the onset of the first psychosis. Many of the participants expressed that their family member fared better living independently than living at home because it was felt that living at home fostered dependence.

The decision to encourage their family member to live independently was not always an agreed upon arrangement and was linked to the issue of enabling versus supporting as described above and uncertainty on how to act. It was a struggle and a decision that was not made lightly. Family caregivers worried about creating dependence on the one hand and having their family member live in inadequate housing on the other. Some participants described how their family member became dependent and lacked the motivation to move towards self-sufficiency while living at home:

> (F4) we realized when he lived at home he slept 20 out of 24 hours and he became increasingly dependent upon his father and I.

> (F9) for the individual, the dependence can be an issue. There was a time where Eric lived here primarily. He was comfortable here and safe here... and it was. It was a very safe place for him. Because of that, we had to do some gentle shoving.

> (F8) When he's lived under our roof and we've provided him with all of the supports it hasn't worked out. He's done better when he's on his own providing for himself.

(F7) He was living at home with us at that time and we made the decision that he couldn't come back home to live with us […] when he was discharged. We felt like if he came home he would never get better, like he would just stay in the basement and that's what it would be like and our life at that time was very hellish.

Family caregivers were faced with the difficulty of finding housing that is supportive and that meets the needs of the individual. Many of the factors they faced were structural. For example, families spoke of a lack of housing options available; inflexibility of support services; social assistance rates that don't meet housing market realities; and private market situations that are of low quality and in poor locations within the city. These structural limitations place a burden on family caregivers and restrict their ability to provide supportive care to their family member.

These structural barriers placed their family member and themselves at the margins of the housing market and impacted the caregiving process in a profound way. A family caregiver, exhausted by the difficulties in finding appropriate housing for their son, simply stated:

(F7) The biggest challenge we encountered in providing care for Patrick was just to get him a decent place to live.

This participant struggled to find appropriate supports to help her son live independently in the community:

(F9) When I looked around for supportive housing... I don't really know if there are any supportive housing [places] for people like my son who are functioning and who are bringing in an income. [He needs] minimal supports. You just need somebody to check in once a week.

When their family members were in housing that met their needs, had high quality and was affordable, it played an important role as a positive mediating factor against the burden experienced by caregivers. A respondent described the feeling they felt when their son finally was able to find the right type of housing:

> (F8) When he was at [group home] it was nice and clean, but you only have a bedroom for privacy and you might have to end up sharing a bedroom. That's not desirable for everybody. [Now he's in] housing that [he] is proud of or comfortable to live in, that's what is supportive to us.

Another participant simply stated:

> (F4) When Geoff is supported with housing, education, it just filters right up to the family.

Marginalization within the Housing Market

Marginalization within the housing market also means living in deplorable housing conditions and with other people who are marginalized within society. Some examples:

> (F2) They were very small rooms. There was a little mattress on the floor. The bathrooms at the end of the hall and the toilet hadn't been flushed. I felt like I was in a nursing home. The fact that they had taken so much money from people... I wouldn't want my son going there.

> (F6) I think Manitoba Housing stinks. The whole idea of Manitoba Housing putting a bunch of poor people together in a big, huge building... and then they wonder why there are problems. It makes me very angry.

> (F8) We looked at Sherbrook and Maryland and along Corydon. There were a few apartments that were horrible. If you are suffering with an illness, any kind of illness, you need light. If you are a healthy person and you are mobile then you can handle a little less light. But if you aren't

feeling well and you are at home most of the time, you need light and a comfortable apartment.

Financial Barriers

The cost of housing in the private market relegated their family member to seeking housing in the inadequate public sector or rooming houses. For example:

> (F8) A major obstacle is cost. It seems that you really could only get a rooming house for the price offered by social assistance.

Participants felt that the costs were so prohibitive that it robbed their family member of the choice of where to live. Parents were often faced with the dilemma of either providing financial assistance to help their family member live independently (and keep their standard of living) or have them lose their housing situation and live in an insecure area, in housing of an inadequate type and poor quality.

A participant described the painful decision they have made and continue to make regarding financially supporting their family member and the fear of losing progress that their son has made towards living a normal and independent lifestyle:

> (F5) So now, if he loses his job, or if he has to take time off for a recovery period and maybe even to be hospitalized, he's going to lose his apartment. Unless I pay for it, he'll lose it. It just keeps going [like that] or I can say no, Jeremy I'm not giving you that, then he'll lose his apartment and then he'll end up downtown. You know... there's no option, no real option.

Another participant supported their family member living independently in a higher quality apartment by providing food and clothing when their social assistance ran out:

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(F7) It's getting harder and harder because housing is more expensive. Any extra money he has comes out of the food allowance but he would rather live on Stradbrook then on Spence. With the amount of money that Patrick has left over he could live maybe for a week or a week and a half. I don't know what would happen if it wasn't for us giving him food or other supports.

For many participants, encouraging and supporting a normal and independent life where they feel the individual is making a social contribution means financial supports are needed to plug the gaps. A participant explained the arrangement she had with her son:

(F9) He does his own cooking and pays his own rent. He works as a security guard [making] minimum wage and he manages his money. I gave him the car; he pays the insurance, but I pay the repairs. He's on pharmacare now. I still support him financially. He has a deductible. This year his deductible will be higher and I pay for that because I don't want him to be punished more by the illness. By and large, he's making an income that he can pay for his rent and groceries.

Housing and Stigma

Participants particularly felt the affects of stigma in the private housing market. For participants stigma was prevalent in both trying to access and keep private market housing. A participant expressed the frustration of their son trying to get out of a difficult housing situation and facing stigma in accessing the private housing market:

(F8) I remember when Aaron wanted to get out of [group home], he was phoning around for whatever he could afford. They didn't want someone on social assistance. I think he did identify that he had a mental illness because he's honest. I think there is stigma in some areas.

In some cases stigma takes the form of discrimination and highlights the tenuous housing situations that many are faced with. One participant recounted the eviction of their son from a private rental suite:

> (F7) They were kicking him out, but they said, oh yeah, we're renovating the block and stuff so you know Patrick has to go because we're taking his suite over and we're using it as a storage area. But they just let him out.

'Downtown' was often referred to as a housing location of last resort; one step away from living on the street. It was often associated with low income, bed bugs, insecure housing tenure, people preying on those who can't defend themselves, poor quality housing, and stigma. For many participants, the stigma they encountered in the housing market was not experienced solely in accessing housing but also in the type and location of housing that is available to people living with mental health issues. This anger towards being marginalized within the housing market was expressed by a participant this way:

> (F6) having access to housing that is not Manitoba Housing, where the housing is just the same as everyone else. That means housing that is not stigmatizing or ghettoizing.

Many of the concerns about being marginalized in the housing market included feelings disempowerment, a loss of choice, removing individuals from their community, and safety. Some examples:

> (F5) If he were in a downtown environment I think it wouldn't be long before he'd be in trouble, he would certainly be vulnerable.

(F9) I know that he looked at different areas and he didn't want to live downtown because of safety concerns. He wanted a safe neighbourhood. That is something that is important for someone with his condition.

Past Experiences and Preferences

As shown in the discussion of normalcy, family caregiver participants were not passive recipients of the struggles they and their family member faced in the public and private housing market. They were active in helping their family member choose, get and keep appropriate housing in both the public and private housing sector; they were involved in supporting their family member to live independently in their home; they provided financial support; they helped to look for housing in the private market; and they advocated for services and supports.

These housing experiences helped to inform their perceptions about the mental health and housing options available in Winnipeg. These past housing experiences and other housing situations that they witnessed also shaped the types of housing options that they helped their family member get access to and try to keep. As a result, the types of housing that these family caregivers preferred were often spoken about in relation to the type of housing that worked for their family member or the type of housing they wished their family member could have access to, in scenarios where the housing situation did not work for their family member.

A participant who had experience working as a nurse expressed her concerns of trying to find a suitable place for her son:

> (F2) They find a lot of low income housing for these people but when you're used to a certain standard of living you don't want to see your child [without] the basics.

Another participant recounted their experience with low-quality social housing options in the inner city.

> (F9) I remember applying for Manitoba Housing. I remember talking to government officials and them saying there isn't a lot available there. What was available was in low-income, rough areas. I remember the individual on the phone telling me that I'm not sure you want your son living in that area. I've experienced myself [that area] delivering hampers for the Christmas Cheer Board. They were having difficulty having people do the downtown. I remember seeing the Manitoba Housing complex. People were living in rooms [that were] ¾ the size of this living room. I like the idea of integrating people. Not everyone living together.

Many participants expressed the importance of housing choice and having housing options that were independent and available within their own community. For example:

> (F8) He lived at [group home] for 4 to 5 months. He hardly lived there. He didn't eat there. He would always come over. He didn't want to go back. It didn't work out [for him] really well. It didn't feel like those were his kind of people. He didn't feel comfortable, it wasn't his choice, and he wanted to come home […] when he moved out [on his own] he started cooking his own meals. He would start contacting his friends again. He had friends who were renting on Balmoral so he could walk over. They saw him as being more capable and he felt more capable. So when 2 of the friends moved out, he moved in with 2 friends on Balmoral and he's still there.

In some instances caregivers advocated directly on their family member's behalf to get them out of unsafe housing conditions:

(F4) There were some violent outbreaks with the two other clients [in the group home] and we were very concerned about Geoff, so we again phoned the social worker and told him he's got to leave, he can't stay there. He got a place in an apartment by himself and he started to heal and become independent.

Participants played an active role in supporting and advocating for their family member to live independently in the community. Housing is perceived a symbol for independence and normalcy. Structural barriers and limitations such as housing quality, availability, social assistance rates, amongst others play a part in determining whether housing is a positive element of the resource base for the individual living with mental health issues and the family caregiver.

As a result, participants often stepped in to plug the gap and to help overcome these structural barriers and marginalization to foster and support their goal of pursuing a normal and independent life. As a consequence, the success of the individual within his/her housing situation translates into success for the family caregiver and the entire family unit.

4.5 Section Discussion

Fighting for Normalcy is the central theme that emerged from the interview data. It is closely linked to the other core themes of Responding to Burden and Stigma, and Housing. Family caregivers largely responded to the impacts of burden, stigma and their difficulties in supporting their loved one to get access to housing and support services, by changing their mindset on what it means to live with someone with a mental illness, by advocating to change the system and by helping their family

member live independently and foster independence. Formal and informal support groups were important to elements of the caregiver support network and helped to alleviate the burden experienced through the caregiving process. Structural barriers placed their family members at the margins of society. This placed a greater burden on them and their family.

The caregiver's experiences with housing were largely negative. The structural limitations (e.g. social assistance rates, quality of housing, types of supports, availability of social and private market housing) increased a sense of burden for caregivers. Despite the negative experiences with housing, normal independent housing was still perceived as a critical component for having access to a normal lifestyle that includes social integration and employment. Caregivers provided financial support, assistance with daily living tasks (e.g. cooking, cleaning, and transportation) and behind the scenes advocacy to ensure their family maintained housing and the opportunity to pursue a normal life.

The next chapter develops the implications of the core themes discussed above and identifies policy recommendations to help address some of the perceived gaps that the interviews reveal.

5.0 Discussion and Recommendations

The final chapter will discuss the insights from the data analysis and provide more thorough analysis of the themes in relation to housing and supports within the housing and mental health system. Further, implications of this thesis will be examined and recommendations provided for informing public policy.

5.1 Summary Review

The literature review revealed some of the major processes of deinstitutionalization in the North American and European context. The application of policies that transitioned the locus of care from the institutional setting towards the community has resulted in people living with mental health issues experiencing institutionalized forms of care in the community, increased homelessness and increased criminalization. Structural barriers have placed people with mental health issues in a precarious and marginalized position within society and in particular the housing sector, making them rely more heavily on their support network of family and friends. As a result, for families, deinstitutionalization has meant taking on greater responsibility over the caregiving process. Caregivers are now more than ever involved in every aspect of their family members' lives. They assist with daily living activities (e.g., cooking, cleaning and transportation), emotional support, financial support (e.g., clothes, entertainment, medication and furniture), housing and advocacy.

The breadth of the caregiving responsibilities has impacted every part of caregiver family life including family, friends, work, leisure and siblings and has resulted in burden and negative impacts on overall family health. All families have to learn how to cope with the illness and the burden, anxiety and fear associated with the illness and the caregiving process. The context for providing supportive care varies. Studies have shown that a large percentage of families provide care within the household, but still many others provide support for people living independently in the community or in supportive housing.

Studies on families and caregivers have primarily focused on burden. These studies have provided the distinction between objective (observable impact of the illness) and subjective (emotional or psychological impacts) burden. Results have shown that subjective and objective burdens were strongly correlated and that higher rates of burden were often associated with types of subjective burden such as worry and grief, as opposed to observable types of burden associated with caregiving such as helping with cooking, cleaning or missing work. Gender analysis has also shown that women tend to be the primary caregivers, are more invested in the caregiving and are more likely to suffer from subjective types of burden such as a sense of loss or grief, whereas men tended to provide secondary roles. Some of the mediating factors that help to alleviate burden include quality support services, the development of strong coping skills, self-help support groups, spousal involvement and the presence of social support networks. Negative interactions with the mental health system have been shown to increase the impacts of burden as a result of interactions with professionals, access to information, lack of supports, lack of

recognition of their role, and lack of involvement in care planning. Stigma also reinforced burden by disrupting links with social support networks and preventing the reaching out for assistance from friends and professionals. These studies have been successful at identifying burden variables and beginning to provide association between these variables. However, more recently, a few studies have started to undertake a more complete approach by looking at caregiving through a longitudinal lens and from the perspective of the caregivers themselves. These have focused on their experiences of dealing with the illness, their coping strategies and how caregiving changes over time.

Family caregivers play an important part in the mental health system and the resource base of the individual living with mental health issues. They support the individual to live independently in the community and minimize demands on health and social systems. Despite their unique role and importance as part of the resource base for individuals with mental health issues, few studies have sought to better understand and explore their perspective and experiences on supports and housing.

5.2 Discussion

The intent of the critical analysis of the family caregiver interviews was to provide an exploration of the views of family caregivers in light of the findings from the literature review. In particular, themes relating to housing, the caregiving experience, and structural limitations were revealed and explored. By delving into the experiences of family caregivers, a group that has traditionally been

marginalized from structural processes and policies that affect them, this thesis seeks to add to our understanding of their needs and recognizes the place of caregivers as legitimate stakeholders in the dialogue to provide more responsive care in mental health and social services.

Fighting for Normalcy

Family caregivers in this set of interviews were actively engaged in a struggle to regain a sense of normalcy for themselves and their family member living with mental health issues. Part of this struggle included dealing with the structural barriers and limitations of the health and social systems and with the preconceived notions and discourse that define mental illness and perpetuate stigma. Consequently, redefining normalcy, familial roles, and independence were a part of that struggle. Burden, stigma, the housing situation and its local context help to shape the characteristics of that struggle.

The notion of fighting for normalcy revealed in the participant interviews has similarities to Ward-Griffin et al's (2005) account of family caregivers working behind the scenes to support their family member with mental health issues. Participants similarly advocated at the individual level for their family member to succeed in school, and to find and retain 'normal' employment and housing. Participants also advocated at the systemic level to change inadequacies within the system. Participants also changed their minds and perceptions about their familial role, confronting their ideas about mental illness, which led to them redefining

normalcy. There are similarities between the experiences and actions of the participants in this study and those in Rose et al. (2002) for confronting the ambiguity of the illness. In both studies 'normalcy' is seen as a goal to be achieved, however housing is not explicitly discussed as a tool for achieving a normal lifestyle by Rose, Mallinson and Walton-Moss, as it is in this study.

Burden and Supports

Participants relied on their support networks, which include family, friends and self-help groups to help mediate the impacts of stress, anxiety, frustration and overall burden experienced by caregivers. This is similar to other studies, which have shown that families (Saunders, 2003), friends (Rose, et al., 2006) and support groups (Ferriter & Huband, 2003) are important elements in caregivers coping with the burden of caregiving. Other mediating factors include access to quality housing and responsive supports from the social health systems. Findings in this study reveal that it isn't enough to simply have the presence of these elements in the caregiver's resource base for a caregiver to be supported, be able to cope and have a positive caregiving experience. The appropriateness, flexibility and ease of access are critical factors determining their success. Whether these elements are positive mediating factors or not can vary over a lifetime of dealing and coping with the illness.

Stigma

Stigma plays a large role in affecting the nature of the relationship with family and friends and in determining whether social networks are positive elements of an individual's resource base. Many participants had to work to overcome the current discourse on mental illness within themselves and their families. Stigma limited their ability to reach out for assistance and to develop strong coping strategies. In some instances, the lack of certain positive elements of a resource base further increased severity of the burden they experienced. These situations were strongly associated with feelings of hopelessness, anxiety and isolation. Participants responded differently to these barriers, but some participants had similar strategies for coping and these included developing support networks between parents, joining advocacy boards, and challenging their families' preconceived notions of what the illness is. As a result, caregivers were active agents trying to shape the circumstances of their particular situation.

Housing Preferences

Studies exploring housing preferences have shown that people living with mental health issues, regardless of their current housing situation, prefer more autonomous housing, whereas families have tended to prefer housing with more supports (Dorvil et al., 2008; Friedrich et al., 1999). Results from this project reveal that participants preferred housing that is normalizing for the individual and that promotes independence. Specifically, preferences included housing that is:

integrated with the general population; located within the individual's community; and non-stigmatizing. Non-stigmatizing housing refers to housing that fits the character (e.g. size, type, scale) of the neighbourhood and the community in which the housing is situated.

Part of the dissonance with the findings in this report and the literature can be in part attributed to methodology. Previous studies did not explore past housing experiences nor did they qualitatively explore preferences. Findings from this study show that housing is perceived to be a critical component of normalization, where the expressed goal is to live as independently as possible. Past housing experiences also impact and help to shape housing preferences. Participants in this study were very critical of the current housing options available for people living with mental health issues. Options offered within the public housing sector often did not meet the needs of their family member and in some cases were stigmatizing. As a result, private housing options that offered a less stigmatizing environment and allowed choice (even if limited due to financial constraints), were seen as more viable, even though many of them were poor quality. In addition, in many cases caregivers felt their family member faired better living independently and had greater opportunities for social integration and normalization (e.g., having friends, going to school and getting employment). Most participants also felt that access to supports was critical in helping their family member live independently, but that these supports should be flexible and meet the needs of the individual in their stage of recovery. There was recognition among participants that housing with more

intensive supports will be needed, but that the goal or focus should be on providing

housing options that foster a more independent lifestyle and normal environment.

Place within the System

The existing data set on a sample of caregivers provided an insight into their

perspectives on care and showed that caregivers were engaged at the individual and

systemic level. This level of engagement was present despite the burden they

experienced as caregivers and the lack of informal or formal processes for them to

be invited into that system. In other words, caregivers can be perceived to be

auxiliary members of a mental health system fighting for recognition as partners

and inclusion into decision-making processes.

Gaps in the Literature

The exploration of the data set also provided an opportunity to better understand

the gaps in our understanding of the needs and priorities of caregivers. In particular,

the analysis revealed the importance of normalized housing as part of an overall

goal of fighting for normalcy and the effect that stigma has on achieving that goal. As

shown above, stigma in the private housing market impacts the ability of individuals

living with a mental health issue to access and keep housing. In public housing,

stigma was primarily discussed in terms of the stigmatizing effects of certain

locations within the city and the type of housing provided. In other words, there is a

gap between what kinds of housing are provided and available for people living with mental health issues and what is needed.

Theoretical Framework and Methodology

Collaborative planning, as a theoretical framework, contributed two important elements to this research project. First, it is respectful of the population being studied, meaning doing research in an area and with a population that has been traditionally excluded and marginalized from the decision making processes requires an approach sensitive to historical issues. Caregivers are a critical component of the health care system and have replaced much of the traditional roles (e.g. housing) that the system used to fulfil. As a result, their experiences, thoughts, needs and priorities need to be brought into the planning process.

Second, collaborative planning seeks to understand concepts of agency, structure, discourse, and power dynamics. This line of inquiry is important because of the historical marginalization that people living with mental health issue and their families have experienced and because of the gap in our understanding of their needs and priorities. Other ways of approaching this type of study, such as a rationalistic approach, would fail to notice themes of agency, structure, discourse and power dynamics critical to the understanding of the caregiver reality. As a consequence, planners need to recognize that the way they approach research studies and public policy, impacts the scope of their work, influences what is

explicitly discussed and what is implicitly understood, and affects who is involved and who is not.

Critical discourse analysis complemented the collaborative planning theoretical framework because of its focus on discourse and power dynamics. The similarities between the two provided a focus and a link between the theory and methodology providing guidance to the research. However, CDA's flexibility in its approach to methodology was both a strength and a weakness for me as part of this research project. The challenge is that for inexperienced researchers, there is a lack of an authoritative step-by-step methodology that can guide the researcher through the analysis. However, this flexibility in choosing methodological tools to help in the data analysis provides strength in being able to adapt the methodology to the circumstances of the data being analysed.

The next two sections discuss the recommendations stemming from the research project for planners and policy makers and some implications for future research.

5.3 Recommendations

The recommendations below are intended to provide direction to the types of changes that should be explored to improve the responsiveness of the social and health systems to the needs of family caregivers and individuals with mental health issues.

1. *Family caregiver integration into care delivery systems*

   Participants spoke about a need to change the system by making it more responsive to the needs of individuals with mental health issues and their families. For programs to be centred on the needs of families, caregivers and/or the resource base of the individual with mental health issues requires further understanding of what those needs are. Further involvement and needs assessment are required both at the systemic level (policy/program formation) and at the service delivery scale. This means making space for family caregivers to influence and shape the development of policies, their delivery and review.

2. *Provision of flexible housing opportunities*

   Participants witnessed their family member being marginalized in the housing market. As a result, participants expressed a need for increased access to housing options that are 'normalizing', meet the needs of the individual and foster independence. A portable housing subsidy, which follows the individual rather than staying with the hosuing, would provide access to higher quality housing and provide greater choice. A portable housing subsidy also reduces stigma by allowing people living with mental health issues with the opportunity to access a greater choice in the type of housing and by allowing people to select housing in the community of their choice. An important component to a portable housing strategy is having the appropriate supports in place that can assist the individual to get and keep

their housing. These supports need to be flexible and responsive to the unique needs of the individual.

3. **_Improved System Navigation_**

Participants experienced stress, anxiety, powerlessness, disenfranchisement and increased burden in dealing with health and social systems. A lack of knowledge of how the system works and how to access the services they need were some of the key concerns identified. System navigation is critical for caregivers to have coordinated care, to more easily access information and services and to be an integral component of the recovery process and resource base of their family member. Hiring patient navigators would help patients and families deal with the challenges associated with navigating a complex, multi-provider system in a culturally sensitive manner. A system navigator that is capable of quickly connecting people to the care they need, would make the difference between frustration and marginalization and empowerment and control.

4. **_Stigma reduction campaigns_**

Societal discourse on mental health creates a stigmatizing environment for families and caregivers. Participants described how stigma had a profound impact on their families and their ability to access the care they needed. Overcoming stigma and its impacts was a personal journey within each

participant's family. Stigma reduction strategies can be important tools to help change the discourse and frame the debate on mental illness. These strategies should not only be directed towards the population in general, but should also be directed towards the different pressure points, or key target areas, that would alleviate burden for families. These areas include: high schools to help identify and support youth at the onset of their first psychosis; and private housing providers and developers to increase their knowledge and make it easier for people living with mental health issues to choose, get and keep housing.

5.4 Implications and Future Research Directions

In light of the findings from this research project, the following are some future research directions involving family caregivers:

- To further explore the meaning of fighting for normalcy for family caregivers, research could include longitudinal analysis and a gender perspective comparing views of both men and women. Consideration could also be given to exploring differences between caregivers who have undergone specific support programs such as EPPIS compared to family caregivers who have not used similar services;

- Explore the differences in experiences and perspectives of caregivers with a focus on particular groups (e.g., young adults, seniors, persons with co-morbidities) and diagnoses (e.g., schizophrenia, bi-polar, etc.);

- Further research is required to better understand how stigma impacts caregiver interactions with their resource base (e.g. family, friends and support groups); and

- To get a better understanding of family caregiver housing preferences, future studies on housing preferences for family caregivers should take into account a longitudinal perspective. Special attention should be given to the past housing experiences and types of housing of where their family member lived.

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