

The Family
Caregiving
Project

FAMILIES & CAREGIVING: Family Systems

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The Family Caregiving Project

The Family Caregiving Project is a research study exploring the experiences of families affected by mental illness. The study was conducted in Ontario, Canada from 2018-2021. The project was funded by the Social Sciences and Humanities Research Council of Canada.

For more information about the project, please go to www.familyguidetomentalhealth.com/family-caregiving-project or contact Charmaine Williams, PhD at charmaine.williams@utoronto.ca

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What defines a family?

- Definitions can be biological, social, and cultural
- Institutional definitions focus on parental ties, legal connections
 - Kinship ties and families built on choice are less recognized
- Families are defined by a group of individuals who may be legally or biologically linked and:
 - Self-identify as connected to each other
 - Have an expectation of that connection continuing over the long term
 - Have an expectation and commitment to caring (emotional support, concern, assistance, etc.) for each other



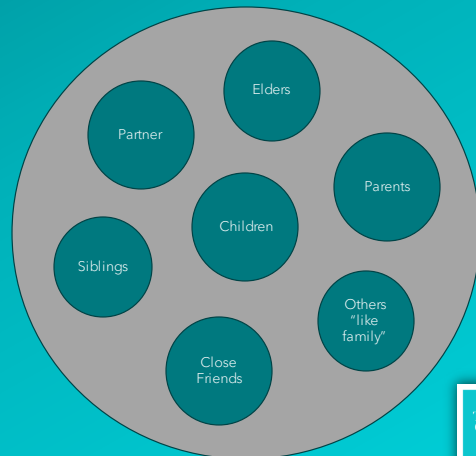
Our definitions of family have changed over time. While this term might once have referred exclusively to people who were biologically or legally connected to each other, we now recognize that families come in many forms and can be created in many ways.

Although cultural definitions of family may be highly variable and flexible, when families interact with institutions (e.g., schools, hospitals, citizenship, employment), they can discover that these systems only recognize family members that fit traditional forms. Families can encounter difficulties in institutions that do not accept their definitions of who is included or excluded from the people they consider family members.

The Family Caregiving Project has chosen an inclusive definition of family that prioritizes individuals defining the relationships that create their family. We understand family to be defined: 1) by the people within it, 2) based on feelings of connection to each other, 3) by the expectation that connection will last for a long time, and 4) by an expectation of caring for each other over that time. That caring can take many forms and is part of the everyday life of families.

The Family System

- A group of individuals working together to meet family needs, mobilize family resources, carry out family tasks
- Boundaries that define the family include and exclude others
- Individuals within the family system have an impact on each other
- Individuals, groups, and institutions outside the family system affect the family unit
- The family system changes over time



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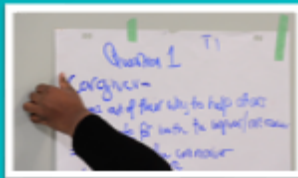
It can be helpful to think about a family as a system. The grouping of individuals within a family system makes them part of something larger with shared functions, shared identity, shared history, shared culture, etc. Individuals within the family play different roles in maintaining the family system. A social boundary around the family system contains those people and shared experiences. It also establishes a division between that family system and other individuals and groups that surround it.

The family system is affected by things that happen internally and externally. Internal influences can include the addition or loss of family members, maturing of family members, or new stressors on individuals in the family; these affect all family members. External influences can include changing social conditions, contacts with other families, or contacts with institutions like schools, religious organizations, or government agencies. These also have an effect on everyone in the family system.

Although there may be periods of time when the family life is predictable and stable, family systems are always in states of change or transformation and, depending on circumstances, families are more or less able to maintain stability through changes.

What defines a “caregiving family”?

- Caregivers are people who regularly provide health, protection, welfare, and maintenance care for a child or adult who is sick, elderly, or has a disability
- The 2018 Canadian General Social Survey showed that 1 in 4 people aged 15 and over were in a caregiving role for an adult with a long-term illness or disability
- Caregiving families provide care for one or more adults in addition to managing other needs in the family



The families this project calls “caregiving families” are in family systems that have been impacted by the need to provide caregiving for one or more adult family members with a long-term illness or disability.

We know from the census research and other surveys that many families provide caregiving for adults. It is likely that we all know families that could be identified as caregiving families.

Caregiving is a usual part of family life. Over a lifetime, families anticipate caregiving for children when they are young and for elders as they age. Caregiving families do that type of caring and they also manage caregiving needs for adults who are affected by long-term illness or disability.

Caregiving families

- The needs associated with caregiving affects family members and family system functioning
- Illness or disability bring families into contact with specific systems and institutions, e.g., healthcare organizations, community support services, government services
- Diversity of caregiving families often means addressing more concerns and facing potential barriers



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When one or more family members are affected by health challenges, energy and resources in the family adjust to support those family members. This, inevitably, affects the energy and resources that are available to other family members and their availability to deal with things outside of the family.

The family system is brought into contact with systems and services that they may never have imagined would be part of their lives. Doctors, hospitals, case managers, rehabilitation, and related services may all become part of family life.

Mental illness affects families across the range of diversity. Families may navigate the personal, social, and institutional experiences associated with health problems while also navigating stressors and problems like racism, homophobia, classism, and other forms of oppression and discrimination. Families that are members of groups that are marginalized, disadvantaged, or stigmatized in society face additional challenges and barriers to getting help and support.

Caregiving and mental health

- Mental illness can be unpredictable and long-term
 - Episodes of illness emerge in context of usual family stressors
 - Usual family stressors can be precursors to episodes of illness
- Mental health and physical health concerns can co-exist, can affect multiple family members
- Periods of hope, worry, crisis affect the mental health of the entire family
 - Young children especially may feel all these things but without having knowledge or understanding of mental health to provide context



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Mental illness is one of many chronic health disorders that are rising in our population. Mental health concerns can emerge or worsen without any warning. A period of illness may be an addition to existing stressors in the family or may follow a period of stress in the family. The unpredictability of mental illness is one of the things that makes it challenging for individuals and families.

Families may have more than one member affected by mental health concerns or have family members that have multiple health concerns. For example, it is common for people with physical health disorders to also develop mental health concerns, adding to the complexity of caregiving needs.

The family system strives to maintain stability through this unpredictability and associated periods of hope, worry, or crisis. The efforts to maintain stability and manage these changes affects the mental health and wellbeing of the entire family system. Young children in the family system can also feel the effects but may not have the capacity or the knowledge to understand what is happening and why.

Caregiving models guiding service provision for families

- **Family burden** (defined in the 1960s, post-deinstitutionalization) refers to physical, psychological, social, financial, and other consequences of caregiving
 - Some caregivers and family members place the needs of the diagnosed individual ahead of their own
 - **Objective burden:** Negative effects on the household and caregiving demands placed on family members, e.g., labour, time, tasks, disruptions, etc.
 - **Subjective burden:** Feelings about caregiving, perceptions of the toll of caregiving, emotional impact
- Some attention to positive aspects of caregiving



For many years, the concept of “family burden” has dominated the way we think about issues faced by caregiving families. Family burden was first identified as an issue in the 1960s when mental health systems shifted care for patients with long-term illness from hospitals to an under-resourced community sector. The system assumed and continues to assume that family members will take on the responsibilities of providing care for family members who are affected by mental illness.

Family burden was the term coined to describe the physical, psychological, social, financial, and other consequences of providing this care. The labours and responsibilities associated with that caregiving were further described in terms of objective and subjective burden. Objective burden referred to the tasks and costs of caregiving. Subjective burden referred to the emotional toll of caregiving and feelings about the value of the caregiving role.

Although there are other terms and models used to describe family experiences associated with mental illness, including some attention to positive aspects of caregiving, the dominant concern of mental health research and practice in this area is addressing stressors experienced by caregivers and family systems.

Service design based on burden

Support caregiving, reduce family stress, manage problematic behaviours

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Support and management of diagnosed individual, individual's symptoms/behaviour

Primary Caregiver

Care Receiver

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Defining the experiences of caregiving families on the experience of burden and stress has had implications for the way services are designed to support families.

Caregivers, who are expected to provide care that the healthcare system does not provide, are provided with services to support their caregiving efforts. These supports are often focused on an individual (usually a woman) who is identified as a primary caregiver and who carries most of the responsibility of providing care, interacting with services, and otherwise attending to the needs associated with managing the mental health of a family member. Others included in the family system are mostly overlooked unless there is an identified need to address stress on the system and problems arising from that stress that affect the person with mental illness.

In parallel, services are directed at managing the mental health concerns of the individual diagnosed. These services are directed at the individual and the family is considered mostly in relation to engaging the primary caregiver in supporting that illness management.

This service design does not give enough attention to the family system as a whole. Both the individual and the person called a primary caregiver are isolated within the family system.

Missing: Experiences of diagnosed individuals

- Diagnosed individuals are rarely included in research about caregiving
- The person with a diagnosis is defined as “the stressor”
 - Perpetuation of stigma and stereotypes
- Conventional approaches reinforce the exclusion of diagnosed individuals
 - False divisions between ‘independent/dependent’, ‘stressed/stressor’, ‘caregiver/care receiver’ are constructed and reinforced



Individuals diagnosed with mental illness have not been included in our thinking about caregiving and mental health. Research in the area very rarely consults diagnosed individuals and instead focuses only on members in the family who are identified as caregivers.

In our dominant thinking about caregiving experience, persons who are living with mental illness are primarily identified as a source of stress and burden for family members. This characterization of diagnosed individuals perpetuates stigma and marginalization for these individuals. In this framing, the person who is living with a mental illness is not seen as a functioning, contributing part of the family system. Instead, those individuals are seen as dependent, stressing and a drain on the caring resources for the family.

It is true that when any family member is experiencing a period of acute illness, there is stress, dependence, and a need to devote additional caring resources to that individuals. However, it is problematic that most of the work on caregiving and mental illness assumes that diagnosed individuals are always stressing and dependent.

Research on caregiving experiences of diagnosed individuals

Diagnosed individuals:

- Express concern about impact of caregiving on other family members
- Experience stress about receiving care
- Dislike passive, dependent positioning in families
- Value roles in the family system
- Contribute to care for others in family, as able
- Expect to give and receive care over the long-term



See Williams & Mfofo-M'Carthy (2006) for more information about this study

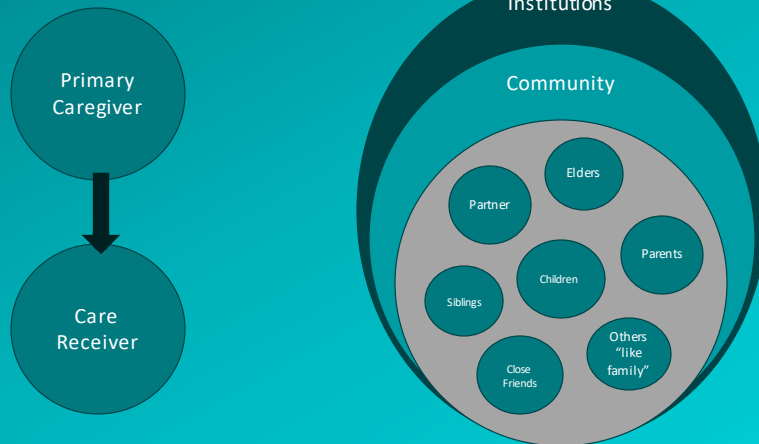
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A study looking at caregiving from the perspective of people diagnosed with mental illness challenges this view.

Participants in that study were not passive recipients of caregiving from family members. They understood and valued the caregiving they received and were concerned about the impact that caregiving had on family members. They actively sought to reduce stress on family members when they could. In addition, they identified stressors associated with being the recipient of caregiving which included concern for others, negotiating independence, and feeling vulnerable.

These individuals valued the roles they had in their family systems and saw those roles as including receiving and giving care like other family members. They understood that all family members took turns giving and receiving care and, although aware that they were recipients of care from others, they expected to also provide caregiving to others as part of long-term family life.

Family system perspective: Managing caregiving family stressors



A family systems perspective affects the way we think about caregiving families managing mental illness.

The model that defines caregiving family experience in terms of a primary caregiver being depleted by demands of care receivers is incomplete and limits the possibilities for how to support families.

A family systems perspective would define every individual in the family system as a family member, connected to the others, giving and receiving care with others. The family systems perspective normalizes that all family members spend time in roles as providers of caregiving and receivers of caregiving, and all family members have shifts in their capacity to provide caregiving over time. The family system adjusts to these changes by mobilizing its resources, which includes available finances, family members, others in the community, and institutional supports that may be available from healthcare, community, or other services.

Periods of mental illness are one of many stressors that affect the caregiving family system. The family system adapts and manages these changes by drawing on internal and external resources. At the same time, it must be recognized that stress can be added to the family system because of issues within or outside the family, and this has an affect on the capacity the family has to manage caregiving.

Family support and services

- Need for caregiving family support and services that:
 - Include diagnosed individuals as part of the family system
 - Seek out family system perspectives on management of stressors
 - Assess and address family mental health
- Need for policies that:
 - Recognize diverse family forms and processes
 - Increase resources and services to support whole family health
 - Support a long-term view of caregiving families as changing, adapting family systems



The healthcare system needs to adapt to a more modern view of caregiving families and their needs. Existing models are based on limiting definitions of families and limiting views of the roles people play in their families, which are not serving the full needs of caregiving families.

Services to families should include all family members, including the individual diagnosed with mental illness, in support for caregiving. The entire family should be part of understanding how caring is being managed, what are the demands and resources in the family system, and how the entire family can be involved in managing caregiving family demands. A focus on family mental health needs to include attention to the well-being of the person with a diagnosed mental illness, attention to the mental health of other family members, and attention to the mental health and well-being of the entire family system.

At the policy level, healthcare organizations and public policy need to reflect the diversity of ways that people create families. This would mean honouring the ways that people have chosen to define their family and relations by including those family members in services and policies for caregiving. Attention to the mental health of families would draw attention to the need for more family support services and the value of supporting whole families to prevent the consequences of unaddressed stress. Current policy is built on assumptions that one person is always a caregiver and another person is always a care receiver. More responsive policy could be adaptable to the changing roles and capacities within the family system and would support the family system instead of individual caregivers and dependents.



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