Discussion Guide

CAREGIVING FAMILIES & MENTAL ILLNESS

In addition to raising awareness and sharing resources, one of the aims of the Family Caregiving Project is to provide tools that communities, professionals, educational settings and other groups can use to deepen understanding of the experiences of caregiving families in the context of mental illness. This Discussion Guide is one of these tools.

How to use this Discussion Guide

We hope this Discussion Guide will be used in gatherings of all kinds to facilitate and encourage conversation about the experience of family caregiving and mental illness. You will see that this document includes discussion questions organized by theme. For each theme, we encourage you to first watch the accompanying YouTube video, and then consider the questions below that will guide you deeper into the issues and concerns of our participants.

Wherever you are using these materials, we suggest working through the 'General Questions' section and then adding on 'Specialized Questions' based on your setting or focus.

We hope you find this discussion guide useful. Should you have any questions, please contact Professor Charmaine Williams at charmaine.williams@utoronto.ca.

GENERAL QUESTIONS

What is a Caregiving Family?

Families promote each other's mental health and see each other through times that are incredibly difficult, navigating who provides care and who receives it. However, not every family in the traditional sense of the term can do that. Many of us are connected to people who we care for and who care for us – and they may not be related.

So, when we talk about family in the Family Caregiving Project, we are also referring to people who are not connected by blood or marriage; those people who we consider to be 'like' family. We often don't see or recognize these people because we can get so stuck in what society defines as family. Taking this expanded and more inclusive idea of family is vital, especially as our population continues to age and experiences increasing rates of complex chronic illness and disability.

We asked our participants about the idea of a 'caregiving family', which would include caregivers and care-receivers. These definitions may describe two separate people within a family, or perhaps a single family member that has experience with both of these roles. Regardless how family members name or label their role in the family, our participants emphasized the dynamic nature of mutual support and care depending on each family member's need on a particular day.

YouTube: Clip 3: Who are Caregiving Families?
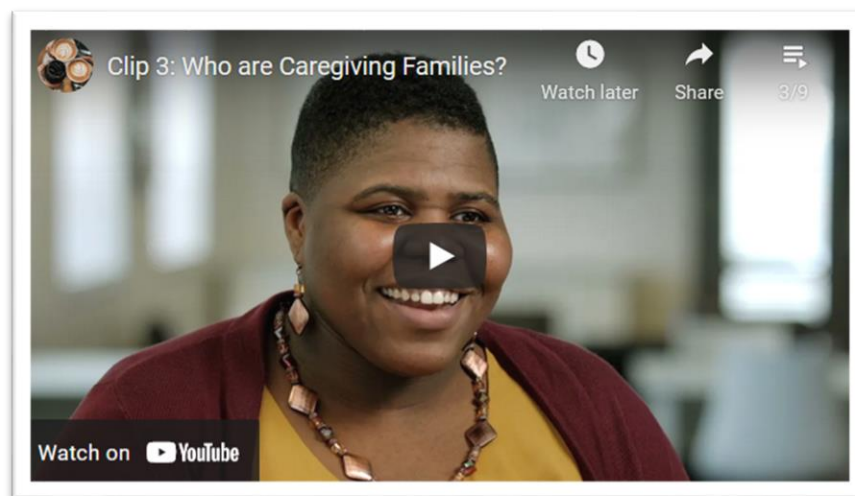
- What is a caregiving family? How did participants describe what this term means to them?
- What are the benefits and challenges of using terms like 'caregiver' and 'care-receiver'? What are some alternatives to these terms that might better capture the sharing of care within families?
- Who do we include when we talk about family? Who may be left out of rigid traditional definitions of 'family' or 'family member'?
- Why is it important for ideas and definitions of family to come from people and not policies?

What Makes Caregiving Hard?

It's no secret that caregiving families face significant hardships as they support one another through experiences of mental illness. However, the story that is told less often is about aspects of our society and mental health care system that make it even harder. We heard about these important topics from our participants with the goal of identifying opportunities to intervene and influence positive changes.

YouTube: Clip 4: Caregiving Challenges
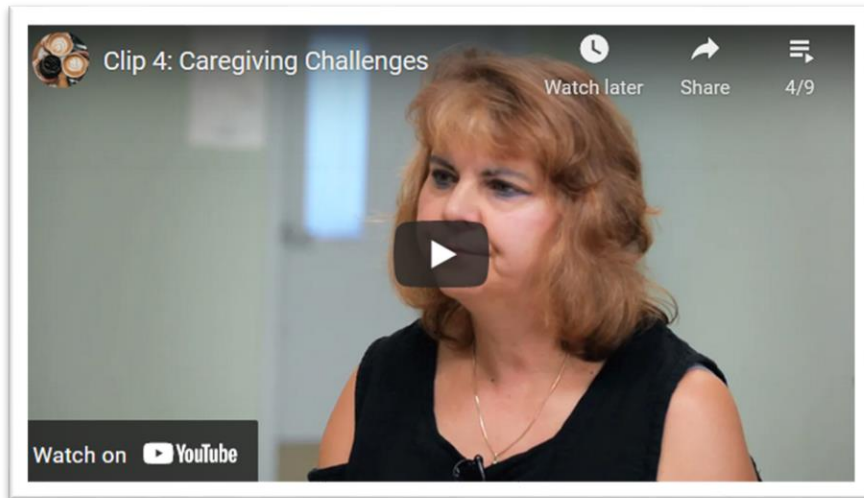
- What are some key challenges that families face in their experiences of mental illness?
- How did barriers show up for families, and how do these impact a family's ability to receive care and support?
- Why is it so important for the whole family to be included in the care of a person with mental illness?
- What are some factors that might affect a person's ability to access mental health care?
- How does stigma show up for caregiving families?

What Makes Caregiving Work Well?

We don't often think or hear about the positives of family caregiving. Much of the news about caregiving talks about 'burden' and the unpaid work that family members provide and shore up the healthcare system. So, what are some stories about family caregiving when it's working well?

YouTube: Clip 5: Advice for Caregivers

- What are some key supports or resources that help families going through experiences of mental illness?
- What values are important for families as they navigate the healthcare system?
- How did the ability to engage in empathy and perspective taking come up in the video?
- Reflect on the role of connection and open communication discussed by participants. What experiences have helped them realize their importance, and how can we promote more of this as a society?
- How could involving families in the development of resources and supports change the mental health care system?

What Do Caregiving Families Want and Need?

Mental illness, like other chronic illnesses, requires long-term supports for individuals and their families. We heard from family members about what they need to be able to feel more at ease as they support each other through mental illness, as well as ideas for how services can be improved for everyone's benefit.

YouTube: Clip 6: Improving Caregiving Experiences

- What helps families as they navigate experiences of mental illness that they do not have predictable access to?
- What recommendations do caregiving families have for system change?
- Why are participants advocating for support for the whole family rather than just for the person with a diagnosis and their primary caregiver?
- How do issues of equity and diversity affect how families access mental health services?
- What ideas do you have on how we can improve our healthcare system for families living with mental illness?

Families, Mental Illness, and Society

Western ideas of family and caregiving may not translate to those of other cultures. There is no one model of effective family functioning caregiving, and we know that families are diverse and have dynamic roles and responsibilities. Intergenerational experiences can also affect how families talk about, cope, and support each other through stigma and mental illness.

Therefore, current systems developed with Western values, at a minimum, may not work well for some families. At their worst, these systems impact marginalized and equity-deserving families as they experience barriers, stigma, and violence while trying to access care.

Instead of assuming what a particular family should look or act like, ask the question: Is this family functioning in a way that promotes the safety, security, and wellbeing of all family members?

YouTube: Clip 7: Social Attitudes & Social Policy

- How do systems of power and privilege affect families and their experience of mental illness?
- How does the current mental healthcare system make it more difficult for family members who are BIPOC, 2SLGBTQ+, low income, disabled, or members of other equity-deserving communities to access support?
- How does the idea of a 'new normal' come up for families as they deal with mental illness?
- What insights did families have about how communities are impacted by changes to policy and funding?
- Talk about intergenerational experiences of mental illness and how this has impact beyond that of the family.

SPECIALIZED QUESTIONS

For Healthcare Settings

Reflect on the ways care is delivered in your setting. Think back to moments you may have interacted with families in your role.

- How are families involved in the care of patients, if at all? Are families generally welcomed, or perhaps less so?
- What gets in the way of families being involved in their family members' care in healthcare settings?
- How do the issues participants raise intersect with consent, capacity, and decision making?
- Have you been in a situation where someone who was not biologically related to a patient was involved as their caregiver? Consider how this situation went. Did you notice any differences in how they were treated among the care team?

For Universities

- Think about how mental health and mental illness is talked about in classes and university services. Are families involved in these conversations?
- For students who may be away from family during their time at university, how might the idea of who is considered family and what 'family caregiving' looks like shift? Does it?
- How can academia support the advancement of 'family caregiving' and other ideas participants wished to be more prominent in society?

For Community Settings

- What differences did you notice about how participants discussed mental illness and family caregiving depending on where they lived?
- What challenges do communities face as they support families with mental illness?
- What advantages do communities have as they support families with mental illness?
- What role do community agencies and settings play in advancing 'family caregiving' and other ideas participants wished to be more prominent in society?

For Youth

- Think about how mental health and mental illness is talked about in school and other places you visit. Are families involved in these conversations?
- Our participants mostly discussed their experience with mental illness from an adult perspective. Does the idea of 'family caregiving' translate to your experience and perspective?
- Did you notice any differences in how you would like family to be involved in your care?