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Theme 1: Roles in Caregiving Families

[Article on Family Systems basic concepts](#)

Key Concepts

- Family systems
- Family roles
- Elasticity/adaptability of the family system

Introduction to Family Caregiving:

Barrio, C., Hernandez, M., & Gaona, L. (2016). The family caregiving context among adults with disabilities: A review of the research on developmental disabilities, serious mental illness, and traumatic brain injury. *Journal of Family Social Work, 19*(4), 328-347.

✓ MacCourt P. (2013). National guidelines for a comprehensive service system to support family caregivers of adults with mental health problems and illnesses. Mental Health Commission of Canada. [Click here for report.](#)

✓ Olasoji, M., Maude, P., & McCauley, K. (2017). Not sick enough: experiences of carers of people with mental illness negotiating care for their relatives with mental health services. *Journal of Psychiatric and Mental Health Nursing, 24*(6), 403-411. [Click here for article.](#)

✓ Ontario Caregiver Organization. (2020). Spotlight on Ontario's Caregivers: COVID-19 Edition. [Click here for report.](#)

✓ Parker, R., Leggatt, M. & Crowe, J. (2010). Public interest and private concern: the role of family carers for people suffering mental illness in the twenty first century. *Australasian Psychiatry, 18*, 163-166. [Click here for article.](#)

✓ Pearson, C. (2015). The Impact of Mental Health Problems on Family Members. Statistics Canada. [Click here for report.](#)

✓ Turcotte, M. (2013). Family caregiving: What are the consequences? Statistics Canada. [Click here for report.](#)

✓ Williams, C. C., & Mfoafo-M'Carthy, M. (2006). Care: Giving, receiving and meaning in the context of mental illness. *Psychiatry: Interpersonal and Biological Processes, 69*(1), 26-46. [Click here for article.](#)

Family Caregiving Roles and Lifeworld:

✓ Dodge, C. E., & Smith, A. P. (2019). Caregiving as Role Transition: Siblings' Experiences and Expectations when Caring for a Brother or Sister with Schizophrenia. *Canadian Journal of Community Mental Health, 38*(2), 35-47. [Click here for article.](#)

✓ Eifert, E. K., Adams, R., Dudley, W., & Perko, M. (2015). Family caregiver identity: A literature review. *American Journal of Health Education, 46*(6), 357-367. [Click here for article.](#)

✓ Hagen, N., Lundin, S., & Petersén, Å. (2012). For better or for worse: Lifeworld, system and family caregiving for a chronic genetic disease. *Culture Unbound, 4*(3), 537-557. [Click here for article.](#)

Mizock, L., Salmonsén, J., & Smith, S. (2022). Family challenges experienced by women with serious mental illness. *Family Relations, 71*(1), 426-438.

Pope, M. A., Jordan, G., Venkataraman, S., Malla, A. K., & Iyer, S. N. (2019). "Everyone has a role": perspectives of service users with first-episode psychosis, family caregivers, treatment providers, and policymakers on responsibility for supporting individuals with mental health problems. *Qualitative health research, 29*(9), 1299-1312.

Sanner, C., & Jensen, T. M. (2021). Toward more accurate measures of family structure: Accounting for sibling complexity. *Journal of Family Theory & Review, 13*(1), 110-127.

✓ Stein, C. H., Gonzales, S. M., Walker, K., Benoit, M. F., & Russin, S. E. (2020). Self and sibling care attitudes, personal loss, and stress-related growth among siblings of adults with mental illness. *American Journal of Orthopsychiatry, 90*(6), 799-809. [Click here for article.](#)

Whitehead, L., Jacob, E., Towell, A., Abu-Gamar, M. E., & Cole-Heath, A. (2018). The role of the family in supporting the self-management of chronic conditions: A qualitative systematic review. *Journal of Clinical Nursing, 27*(1-2), 22-30.

Theme 2: Relationships in Caregiving Families

Key Concepts

- Managing a chronic illness or disability as a family
- Topics to be addressed in family therapy/family meetings
- Acceptance
- Unconditional support

Managing Chronic Illness and Disability in Families:

✓ Ali, L., Ahlström, B. H., Krevers, B., & Skärsäter, I. (2012). Daily life for young adults who care for a person with mental illness: A qualitative study. *Journal of Psychiatric and Mental Health Nursing, 19*(7), 610-617. [Click here for article.](#)

Bevan, J. L., Urbanovich, T., & Vahid, M. (2021). Family communication patterns, received social support, and perceived quality of care in the family caregiving context. *Western Journal of Communication, 85*(1), 83-103.

✓ Dorian, M., Ramirez Garcia, J. I., López, S. R., & Hernández, B. (2008). Acceptance and expressed emotion in Mexican American caregivers of relatives with schizophrenia. *Family Process, 47*(2), 215-228. [Click here for article.](#)

✓ Helgeson, V. S., Jakubiak, B., Van Vleet, M., & Zajdel, M. (2018). Communal coping and adjustment to chronic illness: Theory update and evidence. *Personality and Social Psychology Review, 22*(2), 170-195. [Click here for article.](#)

✓ Muhlbauer, S. A. (2002). Navigating the storm of mental illness: phases in the family's journey. *Qualitative Health Research, 12*(8), 1076-1092. [Click here for article.](#)

✓ Rosland, A. M., Heisler, M., & Piette, J. D. (2012). The impact of family behaviors and communication patterns on chronic illness outcomes: a systematic review. *Journal of Behavioral Medicine, 35*(2), 221-239. [Click here for article.](#)

Areas for Family Therapy:

Knudson-Martin, C., McDowell, T., & Bermudez, J. M. (2017). From Knowing to Doing: Guidelines for Socioculturally Attuned Family Therapy. *Journal of Marital and Family Therapy.*

✓ Madsen, W. C. (2014). Taking it to the Streets: Family Therapy and Family-Centered Services. *Family Process, 53*(3), 380-400. [Click here for article.](#)

✓ Sundet, R. (2011). Collaboration: Family and therapist perspectives of helpful therapy. *Journal of Marital and Family Therapy, 37*, 236–249. [Click here for article.](#)

✓ Watts-Jones, T. D. (2010). Location of self: Opening the door to dialogue on intersectionality in the therapy process. *Family Process, 49*(3), 405-420. [Click here for article.](#)

Wilcox, M. M. (2022). Oppression is not “culture”: The need to center systemic and structural determinants to address anti-Black racism and racial trauma in psychotherapy. *Psychotherapy.*

Theme 3: Sustaining Caregiving Families

Key Concepts

- Family Mental Health
- What self-care is and isn't

Family Mental Health:

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 well-being of the entire family system. The entire family should be part of understanding how caring is being managed, what demands and resources exist in the family system, and how the entire family can be involved in managing caregiving. Support services should include all family members, including the individual diagnosed with mental illness.

This perspective goes beyond “family engagement” in the treatment and care of the person with mental illness, and provides assessment and services that:

- Include diagnosed individuals as part of the family system;
- Seek out family system perspectives on the management of stressors; and
- Assess and address family mental health.

✓ Ong, H. S., Fernandez, P. A., & Lim, H. K. (2021). Family engagement as part of managing patients with mental illness in primary care. *Singapore Medical Journal*, 62(5), 213. [Click here for article.](#)

Roy, R., Jagannathan, A., & Thirthalli, J. (2022). Need for Family-Centric Rehabilitation to Mitigate Socio Genesis of Mental Illness: Case Scenarios. *Journal of Psychosocial Rehabilitation and Mental Health*, 1-7.

Thekkumkara, S. N., Jagannathan, A., Jadhav, P., Durgoji, S. K., Muliyaala, K. P., Angothu, H., & Reddi, V. S. K. (2020). Family centric rehabilitation for persons with mental illness in India: Conceptual framework using evidence-based case studies. *Asian Journal of Psychiatry*, 54, 102344.

Approaches to Self-Care:

✓ Family Care Alliance. (2012). *Taking care of you: Self-care for family caregivers.* [Click here for article.](#)

✓ Karimirad, M. R., Seyedfatemi, N., Mirsepassi, Z., Noughani, F., & Cheraghi, M. A. (2022). Barriers to Self-Care Planning for Family Caregivers of Patients with Severe Mental Illness. *Journal of Patient Experience*, 9, 23743735221092630. [Click here for article.](#)

Hope in Family Caregiving:

Bland, R., & Darlington, Y. (2002). The nature and sources of hope: Perspectives of family caregivers of people with serious mental illness. *Perspectives in Psychiatric Care*, 38(2), 61-68.

Duggleby, W., Lee, H., Nikolaichuk, C., & Fitzpatrick-Lewis, D. (2021). Systematic review of factors associated with hope in family carers of persons living with chronic illness. *Journal of Advanced Nursing*, 77(8), 3343-3360.

Theme 4: Structural and Social Issues affecting Caregiving Families

Key Concepts

- Socio-ecological framework (Bronfenbrenner’s Ecological Systems Theory)
- Feminist Family Theory
- Structural violence
- Intersectionality

Structural and Social Issues Affecting Caregiving:

Few-Demo, A. L., & Allen, K. R. (2020). Gender, feminist, and intersectional perspectives on families: A decade in review. *Journal of Marriage and Family*, 82(1), 326-345.

✓ Vassilev, I., Rogers, A., Sanders, C., Kennedy, A., Blickem, C., Protheroe, J., ... & Morris, R. (2011). Social networks, social capital and chronic illness self-management: a realist review. *Chronic Illness*, 7(1), 60-86. [Click here for article.](#)

✓ Williams, C. C. (2018). Caregiving under siege: An argument for critical social work practice with families. *Canadian Social Work*, 20, 72-87. [Click here for article.](#)

Stigma:

✓ Earnshaw, V. A., Quinn, D. M., & Park, C. L. (2012). Anticipated stigma and quality of life among people living with chronic illnesses. *Chronic Illness*, 8(2), 79-88. [Click here for article.](#)

✓ González-Torres, M. A., Oraa, R., Arístegui, M., Fernández-Rivas, A., & Guimon, J. (2007). Stigma and discrimination towards people with schizophrenia and their family members. *Social of Psychiatry and Psychiatric Epidemiology*, 42(1), 14-23. [Click here for article.](#)

✓ Muralidharan, A., Lucksted, A., Medoff, D., Fang, L. J., & Dixon, L. (2016). Stigma: a unique source of distress for family members of individuals with mental illness. *The Journal of Behavioral Health Services & Research*, 43(3), 484-493. [Click here for article.](#)

✓ Smith, J. M., Knaak, S., Szeto, A. C., Chan, E. C., & Smith, J. (2022). Individuals to Systems: Methodological and Conceptual Considerations for Addressing Mental Illness Stigma Holistically. *International Journal of Mental Health and Addiction*, 1-13. [Click here for article.](#)

✓ van der Sanden, R. (2015). Stigma by association among family members of people with mental illness. *Universitaire Pers Maastricht*. [Click here for report.](#)

✓ Wong, Y. L. I., Kong, D., Tu, L., & Frasso, R. (2018). "My bitterness is deeper than the ocean": understanding internalized stigma from the perspectives of persons with schizophrenia and their family caregivers. *International Journal of Mental Health Systems*, 12(1), 14. [Click here for article.](#)

Discrimination:

✓ Jimenez, D. E., Park, M., Rosen, D., hui Joo, J., Garza, D. M., Weinstein, E. R., ... & Okereke, O. (2022). Centering Culture in Mental Health: Differences in Diagnosis, Treatment, and Access to Care Among Older People of Color. *The American Journal of Geriatric Psychiatry*. [Click here for article.](#)

Knaifel, E. (2022). Immigrant Caregivers: The Double Burden Experience of Immigrants Caring for a Family Member With Severe Mental Illness. *Community Mental Health Journal*, 58(3), 606-617.

✓ McCann, E., & Brown, M. J. (2019). The mental health needs and concerns of older people who identify as LGBTQ+: A narrative review of the international evidence. *Journal of Advanced Nursing*, 75(12), 3390-3403. [Click here for article.](#)

Williams, M. T. (2020). *Managing microaggressions: Addressing everyday racism in therapeutic spaces*. Oxford University Press. [Click here for more info about book.](#)

✓ Resource: [Mental Health For Everyone](#)

Theme 5: Healthcare system interactions with caregiving families

Key Concepts

- Crisis Theory
- Nature of crisis
- Peer support and peer service providers
- Collaborating with families

Crisis:

✓ Baumgardt, J., & Weinmann, S. (2022). Using Crisis Theory in Dealing With Severe Mental Illness—A Step Toward Normalization?. *Frontiers in Sociology*, 7. [Click here for article.](#)

✓ Lavoie, J. A. (2018). Relative invisibility: An integrative review of carers' lived experiences of a family member's emergency mental health crisis. *Social Work in Mental Health*, 16(5), 601-626. [Click here for article.](#)

✓ Thomas, K. C., Owino, H., Ansari, S., Adams, L., Cyr, J. M., Gaynes, B. N., & Glickman, S. W. (2018). Patient-centered values and experiences with emergency department and mental health crisis care. *Administration and Policy in Mental Health and Mental Health Services Research*, 45(4), 611-622. [Click here for article.](#)

Peer Support:

✓ Bochicchio, L., Stefancic, A., McTavish, C., Tuda, D., & Cabassa, L. J. (2021). "Being there" vs "Being direct:" Perspectives of persons with serious mental illness on receiving support with physical health from peer and non-peer providers. *Administration and Policy in Mental Health and Mental Health Services Research*, 48(3), 539-550. [Click here for article.](#)

✓ Galloway, A., & Pistrang, N. (2019). "We're stronger if we work together": experiences of naturally occurring peer support in an inpatient setting. *Journal of Mental Health*, 28(4), 419-426. [Click here for article.](#)

✓ Hughes, J., Wood, E., & Smith, G. (2009). Exploring kidney patients' experiences of receiving individual peer support. *Health Expectations*, 12(4), 396-406. [Click here for article.](#)

✓ Lennox, R., Lamarche, L., & O'Shea, T. (2021). Peer support workers as a bridge: a qualitative study exploring the role of peer support workers in the care of people who use drugs during and after hospitalization. *Harm Reduction Journal*, 18(1), 1-9. [Click here for article.](#)

Mercuri, A., Burton, J., Epifanio, A., & McKenzie, P. (2022). Understanding carer experiences in public adult mental health services using Carer Peer Support data. *Advances in Mental Health*, 1-20.

Mutschler, C., Bellamy, C., Davidson, L., Lichtenstein, S., & Kidd, S. (2022). Implementation of peer support in mental health services: A systematic review of the literature. *Psychological Services*, 19(2), 360.

Watson, E. (2017). The mechanisms underpinning peer support: a literature review. *Journal of Mental Health*.

Theme 6: Systemic Issues Affecting Caregiving Families

Key Concepts

- Social and structural determinants of health
- Structural violence, oppression, discrimination
- Marginalizing policies and resource distribution (rural/urban)
- Patient-led research and consumer-driven approaches

Social and Structural Determinants of Health:

Berry, O. O., Londoño Tobón, A., & Njoroge, W. F. (2021). Social determinants of health: the impact of racism on early childhood mental health. *Current Psychiatry Reports*, 23(5), 1-10.

✓ Hastings, P. D., Guyer, A. E., & Parra, L. A. (2022). Conceptualizing the influence of social and structural determinants of neurobiology and mental health: Why and how biological psychiatry can do better at addressing the consequences of inequity. *Biological Psychiatry: Cognitive Neuroscience and Neuroimaging*. [Click here for article](#).

✓ L'Heureux, T., Parmar, J., Dobbs, B., Charles, L., Tian, P. G. J., Sacrey, L. A., & Anderson, S. (2022). Rural family caregiving: A closer look at the impacts of health, care work, financial distress, and social loneliness on anxiety. *Healthcare*, 10(7), 1155. [Click here for article](#).

Savelle, R. M., Nykänen, I., Schwab, U., & Välimäki, T. (2022). Social and Environmental Determinants of Health Among Family Caregivers of Older Adults. *Nursing Research*, 71(1), 3-11.

Walker, D. K. (2021). Parenting and social determinants of health. *Archives of Psychiatric Nursing*, 35(1), 134-136.

✓ Young, H. M., Bell, J. F., Whitney, R. L., Ridberg, R. A., Reed, S. C., & Vitaliano, P. P. (2020). Social determinants of health: Underreported heterogeneity in systematic reviews of caregiver interventions. *The Gerontologist*, 60(Supplement_1), S14-S28. [Click here for article](#).

Structural Violence and Oppression:

✓ Anchuri, K., Jacox, N., Andreychuk, T., & Brown, A. (2021). Structural Violence Education: A Critical Moment for Psychiatric Training. *The Canadian Journal of Psychiatry*, 66(9), 785-787. [Click here for article.](#)

✓ Anderson, B. (2021). The Structural Violence of Indigenous Suicide Prevention Policies in Canada. *Anthropology in Action*, 28(3), 22-34. [Click here for article.](#)

✓ Hamed, S., Thapar-Björkert, S., Bradby, H., & Ahlberg, B. M. (2020). Racism in European health care: structural violence and beyond. *Qualitative health research*, 30(11), 1662-1673. [Click here for article.](#)

✓ Reinhart, W. (2020). *Exploring Ethnoracial Minority Clients' Experiences of Oppression During Counselling with White Counsellors* (Doctoral dissertation, Université d'Ottawa/University of Ottawa). [Click here for article.](#)

Reynolds, V. (2020). Trauma and resistance: 'Hang time' and other innovative responses to oppression, violence and suffering. *Journal of Family Therapy*, 42(3), 347-364.

✓ Thompson, L. (2021). Toward a feminist psychological theory of "institutional trauma". *Feminism & Psychology*, 31(1), 99-118. [Click here for article.](#)

✓ Weine, S., Kohrt, B. A., Collins, P. Y., Cooper, J., Lewis-Fernandez, R., Okpaku, S., & Wainberg, M. L. (2020). Justice for George Floyd and a reckoning for global mental health. *Global Mental Health*, 7. [Click here for article.](#)

Williams, M. T., Rosen, D. C., & Kanter, J. W. (2019). *Eliminating race-based mental health disparities: Promoting equity and culturally responsive care across settings*. New Harbinger Publications. [Click here for more info about book.](#)

Patient-Led Research and Consumer-Driven Approaches:

✓ Kockzur, S., Halton, E., & Pintson, K. (2018). I Promised We'd Get Help: The Parent's Journey—Experiences of Parents and Family of Youth Visiting the Emergency Department with Mental Health Concerns. University of Calgary, Calgary, AB. [Click here for article.](#)

Singh, S., Burns, K. K., Rees, J., Picklyk, D., Spence, J., & Marlett, N. (2018, March). Patient and family engagement in Alberta Health Services: improving care delivery and research outcomes. In *Healthcare Management Forum* (Vol. 31, No. 2, pp. 57-61). Sage CA: Los Angeles, CA: SAGE Publications.

✓ Vojtila, L., Ashfaq, I., Ampofo, A., Dawson, D., & Selby, P. (2021). Engaging a person with lived experience of mental illness in a collaborative care model feasibility study. *Research Involvement and Engagement*, 7(1), 1-8. [Click here for article.](#)