METHODS IN PRACTICE:
Doing Qualitative and Arts-based Health Research with Children and Youth

Brenda Gladstone, 
The Hospital for Sick Children

EVALUATION OF SUPPORTS FOR FAMILY CAREGIVERS OF CHILDREN WITH MEDICAL COMPLEXITY

Karen Spalding¹, A. Paul Williams², Cindy Bruce-Barrett³, Allie Peckham², David Rudoler², David Salib¹, Tommy Tam², Jillian Watkins²

¹Ryerson University, ²University of Toronto, ³The Hospital for Sick Children

(First presentation in a series of knowledge translation initiatives introduced by IMPAKT - the partnership between Sick Kids and Ryerson FCS)
Methods in Practice: Doing Qualitative and Arts-based Health Research with Children and Youth
Dr. Brenda Gladstone, The Hospital for Sick Children

Abstract:
In this presentation we will consider how research with young people is a distinctive approach to studying health phenomena; and what it might mean to “give voice” to participants in our studies. Drawing on different disciplinary ways of thinking about children, and childhood, together with examples from my program of research in children’s mental health, we will discuss strategies for generating and translating knowledge; and the challenges to developing a more reflexive and ethical research practice with young people.

Biography:
Dr. Brenda Gladstone is a Research Scientist in the Community Health Systems Resource Group at The Hospital for Sick Children. She is a health sociologist with a PhD from the Dalla Lana School of Public Health, University of Toronto. For her doctoral work she used ethnographic observations, informal interviews and critical discourse analysis to examine participants’ responses to a psycho educational support group for children of parents with mental illnesses. In her research capacity at SickKids she uses theoretically informed qualitative and arts-based methodologies in CIHR- and SSHRC- funded studies to investigate help-seeking pathways to mental health care from the perspective of young people experiencing, or ‘at ultra high-risk’ of psychosis. Brenda is Adjunct Lecturer in the Lawrence S. Bloomberg Faculty of Nursing at the University of Toronto where she teaches graduate courses in qualitative methodology at the Centre for Critical Qualitative Health Research.
Dr. Gladstone’s research has focused on the use of qualitative and quantitative methods to examine health and mental health issues with an emphasis on intensive interviewing, participant observation and the facilitation of focus groups. She also has extensive experience in facilitating parent/family support groups. Research Interests: Psychosocial experiences of children of parents with mental illnesses; help-seeking pathways in first episode psychosis; young people ‘at risk’ of mental health difficulties; sociology of (mental) health/illness; sociology of childhood; qualitative methodology; ethnography; participant observation; critical discourse analysis; arts-based research methods.
Evaluation of Supports for Family Caregivers of Children with Medical Complexity
Karen Spalding, RN, PhD¹, A. Paul Williams, PhD.², Cindy Bruce-Barrett³, Allie Peckham², David Rudoler², David Salib¹, Tommy Tam², Jillian Watkins²
¹Ryerson University, Toronto, Canada; ²University of Toronto, Toronto, Canada; ³The Hospital for Sick Children, Toronto, Canada

Advances in medical technology mean that more Children with Medical Complexity (CMC) -- those experiencing “medical fragility, chronicity and complex health needs” -- are surviving into adulthood and more are living longer in the community. This places unprecedented demands on family caregivers who, in addition to normal parenting responsibilities, now provide specialized medical care (e.g., suctioning, tube-feeding, oxygen) often 24 hours a day, seven days a week. As a result, caregivers can experience stress, health problems and burnout; in turn, CMC may “default” to hospital and institutional care. The Caregiver Framework (CF), led by the Hospital for Sick Children, provides specially trained care managers (Key Workers) with budgets (averaging $3500/caregiver/year) to engage “at risk” caregivers in a process of problem-identification and problem-solving, leading to the co-creation of individualized packages of health and social supports. This presentation will describe the work of the evaluation team that utilized qualitative and quantitative results from in-depth interviews with Key Workers and staff; and analysis of caregiver surveys, caregiver risk assessments and care plans. Fifty-two “at risk” caregivers participated in the Caregiver Framework and although there was no measurable decline in caregiver stress, caregivers felt more confident, more in control of their lives, and more able to continue to care for themselves, their child and their family.