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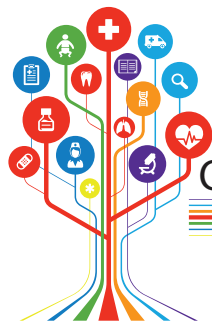
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Implementation and Maintenance Evaluation of the School Oral Health Program in Kuwait

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Objectives: The purpose of this study was to (a) explore the factors affecting the implementation of Kuwait School Oral Health Program (SOHP) procedures and (b) identify factors influencing program maintenance over the past three decades. **Methods:** A qualitative focused ethnography approach was employed. An interview guide inspired by the ecological health framework and RE-AIM evaluation model directed our data collection through in-depth and focus group interviews with dental care providers, key informants in the Kuwait Capital Education Area, and decision policy makers in the SOHP. The interviews were recorded and transcribed verbatim. Thematic analysis of data was performed. **Findings:** Thirty participants contributed to this study. There were 13 dental care providers, four team leaders, nine key informants, and four policy makers in four in-depth and four focus group interviews. Data analysis revealed two main categories influencing successful program implementation: (a) SOHP structure and characteristics including prevention protocol and resources and (b) school environment characteristics including schools' engagement, however, at a policy

level, maintenance dimension. Three main categories emerged related to chronological phases of the program journey: (a) initiation, (b) expansion, and (c) sustainability. At the initiation phase, the role of gatekeepers, advocate leadership, and employing evidence-based dentistry was the main facilitators for establishing the program. At the expansion phase, proactive organizational change led to developing a solid infrastructure. This led to the sustainability phase, which was characterized by awareness by the policy makers of population dental care need and sustained public funding. These elements were the main facilitators to successful program maintenance. Yet, some program constructs showed weak sustainability. For example, the expansion of school-based fixed clinics was implemented due to a serious oral health-care need among schoolchildren as a reactive organizational change due to the Second Gulf War. However, numbers of school-based fixed clinics declined dramatically and were replaced by mobile prevention dental clinics due to unsupported environment, power dynamics, and cost–benefit reasons. **Conclusions:** Kuwait SOHP succeeded in implementing and maintaining school-based prevention procedures over 30 years, yet many program constructs showed poor sustainability. Revisiting program vision, theory, and recognition of elements related to successful implementation and maintenance will allow decision and policy makers to focus on pursuing means to improve capacity for more efficient and successful implementation of the program. This study provides insights that can be shared with wider national and international settings.



Engaging People Living With HIV and Health-Care Providers in the Design and Pilot of a User-Centered Strategy to Improve ART Adherence Among MSM Living With HIV in Mexico

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High adherence to antiretroviral therapy (ART) is essential to improve survival rates among people living with HIV and reduce HIV transmission. Unfortunately, studies show that adherence levels to ART are not optimal. In Mexico, men who have sex with men (MSM) are one of the most affected populations by HIV; nevertheless, few studies have focused on understanding the barriers and facilitators influencing their adherence. This project's first-stage objective was to develop a user-centered strategy to improve ART adherence among MSM starting ART in Mexico. To enhance participants' involvement and translate their perspectives into a strategy, we combined qualitative methods with "design thinking," a marketing approach used to develop user-centered products. In 2016, 37 MSM living with HIV participated in six focus groups discussions, and nine semistructured interviews were conducted with health-care providers. A team discourse analysis approach was used to identify main themes. Design thinking was then used to identify patients' journey after being diagnosed, their profiles according to their experience while taking ART, and the best elements to design the strategy. We found that MSM's barriers and facilitators to adherence are not static and might undergo changes throughout different stages of adjustment to ART. Based on these results, we designed a strategy that focuses on habit formation, with multiple levels of support mechanisms including experienced MSM living with HIV as support peers. Results from this stage were crucial to understand the motivations that will engage both newly and previously diagnosed MSM in the strategy's pilot stage.

Adapting the Group Antenatal Care (G-ANC) Model to the Mexican Context

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Jacqueline Elizabeth Alcalde-Rabanal, *National Institute of Public Health of Mexico*

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Group antenatal care (G-ANC) is a model of antenatal health care where all clinical, educational, and support care happen in a group context with multiple health-care professionals as

facilitators. G-ANC is a midwife-led model focused on supporting women to learn from each other's experiences in a supportive environment. To date, studies in diverse U.S. populations have demonstrated improvements in self-efficacy for birth, high levels of satisfaction, and reductions in caesarean deliveries and preterm births. It is not known whether the G-ANC model will be feasible or acceptable in other settings. The aim of this study was to adapt G-ANC to the context of the Mexican health system and assess feasibility and acceptability by women and health-care personnel. We first worked with local health professionals to adapt the model, with attention to national clinical guidelines and cultural acceptability. We have trained 29 health professionals and implemented our model Consulta Prenatal en Grupo in four clinics and have enrolled 78 of the 140 women to date. Our feasibility study relies on qualitative (6 focus groups and 17 in-depth semistructured interviews) and quantitative (measures of self-efficacy and satisfaction) data with women and providers. Preliminary results suggest a high level of satisfaction with the model among women. Women with their first pregnancies mention feeling less stress for birth due to having heard other women's birth experiences in group. Findings from the project (anticipated Spring 2018) will be used to inform decisions about expanding the G-ANC model in Mexico.

Narratives of Living With Chronic Obstructive Pulmonary Disease (COPD): Engaging the Voices of People Experiencing Social Isolation

Marcy G. Antonio, *University of Victoria*

Laurene Sheilds, *University of Victoria*

Anne Bruce, *University of Victoria*

To have successful public engagement requires citizens who are willing to share their experiences. However, people living with the greatest burdens of illness may also be the most difficult to locate and engage. Chronic obstructive pulmonary disease (COPD) is an illness that exemplifies unique challenges for public engagement. According to the literature, COPD is underdiagnosed and, compared to other fatal conditions, has fewer dedicated research, community, and palliative care resources. With smoking viewed as the most common risk factor for COPD, the resulting shame and victim blaming may further discourage self-identification and sharing of illness experiences and compound social isolation. Within the context of a large narrative study, this presentation will focus on how social isolation is experienced by people living with COPD and their family members. Twenty-two participants were interviewed up to 3 times over 18 months, six of which were dyads. Shared narratives revealed a shrinking physical world and limited connections to friends, families, advocates, and other individuals living with COPD. Participants described the signage that warned visitors on entry and the visibility and vulnerability of being "out in community" with their oxygen support. People often lived alone and spoke of the physical fatigue related to

COPD and the “scary” experience of acute breathing difficulties. During these events, they were hesitant in connecting with others, especially health-care practitioners. The findings from this narrative study will further illuminate the importance of listening to the voices within an illness population that experiences increasing frailty, isolation, and potential stigmatization.

Youth- and Art-Centered Methodologies to Understand Access to Mental Health Services Among Homeless Youth

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Srividya Iyer, *McGill University*

Abdel-Baki, *Université de Montréal*

With most mental illness beginning in youth, the homeless youth population reports high level of unmet mental health needs. In Montreal, Anglophone and Allophone (who speak neither French nor English) homeless youth, as linguistic minorities, face additional problems communicating about mental illness or finding appropriate services. The objective of the study is to understand where and how homeless Anglophone and Allophone youth access mental health-care and allied services and what hinders or facilitates access. Two arts-based qualitative research methods, photovoice and community mapping, were chosen to engage youth in gathering creative and representative information. In this presentation, we discuss the values of our art-based methods and their potential for illustrating the realities of a complex intersectionality between mental illness, youth, homelessness, and belonging to a linguistic minority group. Community mapping—Participants will draw maps of their “community”: resources they use and places providing help related to their mental health. Photovoice—Participants will take pictures that represent their views on mental health, available resources, and factors influencing mental health and well-being (e.g., language). Follow-up focus groups will enable youth to express their emotions and perceptions toward mental illness and related services. These methodologies allow for a common language (art) between the various linguistic minorities and the francophone homeless youth populations. They can yield insights on nomadic/territorial behavior in homeless youth and how it impacts access to mental health and allied services. Finally, gathering youth-led information could generate new topics of interest to better understand homeless youth realities.

Assessing Day-to-Day Perceptions of Risk Among People With Disability

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Geoffrey Edwards, *Laval University*

Ernesto Morales, *Laval University*

People with disability experience risk on a daily basis through their diverse interactions with the environment such as moving about outside, crossing the street, or simply managing a home.

Based on their past experiences and the need to respect their capabilities, they develop a decision-making process to ensure their own safety. This process meets their individual requirements and hence varies from one person to another. To investigate both perceptions of risk and risk management strategies, we developed a qualitative study based on semistructured interviews across a wide range in disability types. Furthermore, to understand how risk factors affect people with disability, we adopted the Disability Creation Process as a conceptual model. Because of the exploratory nature of the work, study size was limited to nine participants initially in a three-by-three structure, three people each with motor, sensory, and cognitive disabilities. This number eventually dropped to seven people who were ultimately interviewed (five individuals had reduced mobility, one was visually impaired, and one was hearing impaired). The study explored the issues of personal safety, risk-taking, risk perception, loss of control, and vertigo. Following a qualitative analysis based on coding the interview transcripts, the study found that although there are differences in how people with disability perceive their personal safety, there is also a great deal of similarity. The results of this work will serve to support the next phase of the project, which seeks to develop inclusive interactive installations that explore the experience of disability.

Prenatal Testing Practice: Mothers' Experiences of Continuing With a Pregnancy After Prenatally Receiving a Diagnosis of Down Syndrome

Sevinj Asgarova, *University of British Columbia*

Tim Stainton, *University of British Columbia*

Jehannine Austin, *University of British Columbia*

Rachelle Hole, *University of British Columbia*

Using social constructionism and interpretive description, the study explored Canadian mothers' experiences of continuing with a pregnancy after prenatally having received a diagnosis of Down Syndrome (DS) for their babies. Twenty-three interviews were conducted with mothers in British Columbia and Ontario. Three primary categories emerged from the data analysis: prenatal testing/decision-making, the adjustment process, and postnatal experiences. The first phase was concerned with the mothers' prenatal testing experience in which they became aware of their child's diagnosis, their initial reactions, and their decision-making. In the second component, mothers reflected on the adjustment process and discussed what they considered to be helpful and unhelpful. The third phase focused on postnatal support and the mothers' resistance to the common perception of having a child with DS. Interaction with medical professionals was a primary theme reported by the participants having had a critical impact on their experiences, both negatively and positively. The majority of mothers in both provinces reported three main areas of dissatisfaction during their prenatal experience. Firstly, the manner of disclosure of the news was very cold, brief, and insensitive and had a biomedical

problem orientation. Secondly, inconsistency in describing all testing options available and lack of explanation of the strengths and limitations of test options. Finally, insistence on terminating the pregnancies, the lack of accurate information about DS, and the lack of provision of up-to-date materials or referral to other parents helped to create a negative prenatal experience. The study results offer considerable implications for genetic counseling to mothers at risk of having a child with DS.

Anal Sex and HIV Transmission Risk Knowledge Among Nigerian HIV-Positive Men Who Have Sex With Men (MSM): A Qualitative Study

Abisola Balogun, *University of Sheffield*
Paul Bissell, *University of Huddersfield*
Muhammad Saddiq, *University of Sheffield*

This study set out to research the experiences of HIV-positive men who have sex with men (MSM) living in Nigeria including accounts about their knowledge and awareness of HIV and its transmission. This topic is particularly important, given the high and rising rates of HIV prevalence among MSM in Nigeria. The study used qualitative interviews and focus groups with Nigerian HIV-positive MSM living in Lagos and Abuja who were purposively sampled from three nongovernmental organizations. A total of 21 adapted narrative interviews and 4 Focus Group Discussions (FGDs) were conducted in 2016. All participants accessed health-care services from facilities providing MSM friendly services, and a majority reported prior experience accessing health-care services from general health-care facilities. Participants reported obtaining HIV knowledge from TV, radio, and other mainstream media sources as well as in schools and villages. Crucially, participants reported very low awareness about the possibility of HIV transmission through anal sex with other men prior to accessing MSM tailored and friendly services. This finding has significant implications, as this lack of knowledge may be a contributing factor to increasing HIV burden among MSM. If the HIV burden is to be reduced in Nigeria, it is imperative that public health interventions focus on creating HIV awareness targeted at addressing the high-risk behaviors, particularly anal sex, of this group.

Intragroup Stigma Among Nigerian HIV-Positive Men Who Have Sex With Men (MSM): A Qualitative Study

Abisola Balogun, *University of Sheffield*
Paul Bissell, *University of Huddersfield*
Muhammad Saddiq, *University of Sheffield*

This study set out to research the experiences of HIV-positive men who have sex with men (MSM) living in Nigeria including

accounts of their ability to manage HIV, access health-care services, and use antiretroviral treatment. This topic is particularly important, given that the same-sex relationships (both male and female) are criminalized in Nigeria. The study reported here used qualitative interviews and focus groups with Nigerian HIV-positive MSM living in Lagos and Abuja. Participants were purposively sampled from three nongovernmental organizations, with a total of 21 adapted narrative interviews and 4 FGDs conducted in 2016. Participants reported a very high level of stigma, discrimination, and extreme violence when sexual practices and HIV status became known by others. As a result, the majority of participants sought to conceal their sexual orientation but found this extremely difficult in their interactions with health service providers, family, and friends. Their experience of stigma and discrimination also encompassed a distinct form of stigma, what participants referred to as “Kito” or stigma, discrimination, and blackmail instigated by other MSM in their communities. Here, we reflect on the relevance of the literature pertaining to stigma and discrimination and discuss what an effective public health intervention to reduce and possibly eliminate intragroup stigma might consist of for this population group.

Preliminary Qualitative Findings From a Theater-Based Health Research Knowledge Translation (KT) Initiative: A Student’s Perspective of Navigating and Optimizing Interdisciplinary Relations

Petrina Barbas, *Ryerson University*
Oona St-Amant, *Ryerson University*

The presentation will highlight in greater depth the preliminary qualitative findings arising from a multidisciplinary project that harnesses the evocative techniques of theater-based knowledge translation (KT) to stimulate critical thinking among undergraduate students about the cultural, ethical, and political dimensions of international health volunteer work. We will speak to the iterative process of drawing from our qualitative health research data in order to produce a play for diverse undergraduate audiences as an interactive teaching tool in the classroom. The play itself offers a critical narrative of the nuances and social processes, such as neoliberalism and neocolonialism, that shape and influence the experience of health volunteer work for international volunteers and for organizations in host countries in the Global South. This presentation will discuss our KT process from an interdisciplinary lens: our methods for evaluating the impact and efficacy of theater as an alternative method for qualitative health research dissemination and the preliminary themes arising from our content analysis of student focus group transcript data. Since the copresenters of this abstract are the students from Nursing and Professional Communication, we will share our experiences

of immersing ourselves in each step of the research process and our role in communicating and collaborating across interdisciplinary boundaries.

Critical Media Health Literacy and Indigenous Adolescents

Deborah Begoray, *University of Victoria*

Alexis Brown, *University of Victoria*

This Pecha Kucha will present a research story on how we have been involving Indigenous teens, their classroom community, and wider public in the creation of health-related graphic novels. These comic style narratives contain student interpretations of health/wellness from a cultural and critical point of view and challenge media interpretations of their health concerns as Indigenous people and as adolescents. Canada's Truth and Reconciliation commission has especially called for education to provide greater understanding and curriculum for Indigenous students. In addition, we know that health risks are high in adolescent age-group and even greater in the Indigenous community. Media in the form of news coverage, advertising, and social platforms too often works against Indigenous teens' well-being. Health education that addresses all these issues, what we term critical media health literacy, has proven in our work to be effectively taught by engaging students in multimedia creation of graphic novels. These novels can then be shared with wider community through uploading on library and school division websites and celebrated through feasts with invited members of parents, tribal councils, elders, and reporters. This research story is especially suited to audio–video formats such as Pecha Kucha due to evocative imagery of the graphic novels students have created.

Reconceptualizing the Social Determinants of Health Through Intersectionality

Jennifer Bell, *University of Alberta*

Sarah Stahlke, *University of Alberta*

Solina Richter, *University of Alberta*

Intersectionality as a concept and method of analysis has been taken up by researchers to describe the complexities of competing social categories and how these categories influence a person's identity and well-being. Notably, intersectionality has only been taken up minimally in literature pertaining to the social determinants of health. This limited use has led to simplistic perspectives on and fragmented solutions to pressing social issues. For example, homelessness has been conceptualized as a housing problem, but research has demonstrated that there are multiple factors that influence a person's housing stability including gender, socioeconomics, immigration status, physical and mental health status, and sexual orientation. These complexities are often underemphasized in government and

agency responses to housing issues. However, if we reconceptualize housing issues using an intersectional perspective, we can develop a transformative, comprehensive, and more nuanced perspective to social issues such as homelessness. In Canada, a long-awaited national housing strategy is to be released shortly. My research will draw on an intersectional approach to critically analyze and review this new housing policy. Ultimately, the goal of this analysis is to evaluate the policy for its capacity to move beyond individualistic and unidimensional responses to homelessness and housing issues and to offer service providers and health professionals (with a focus on nurses) new ways of understanding and addressing this complex social problem.

Uncaring Nurses: A Qualitative Study Examining Violence in Nursing Academia

Renee Berquist, *St. Lawrence College*

Isabelle St-Pierre, *Université du Québec en Outaouais*

Dave Holmes, *University of Ottawa*

Workplace violence is an area of increasing concern worldwide. The psychological and societal consequences of violence in nursing academia have been identified to be harmful to faculty and students, resulting in negative consequences for nursing as a profession. To address this, a better understanding of the culture of nursing academia is required. Workplace violence, including coworker to coworker, results from a relationship characterized by an imbalance of power. Power imbalances exist within academic settings that foster and promote mistreatment. The purpose of this study was to increase understanding of faculty to faculty violence in nursing academia. Guided by a theoretical framework incorporating the perspectives of Mason and Foucault and specifically on the concepts of violence, power, knowledge, difference, and resistance, this study focused on the aspects of the social and cultural work environment and organizational policies and procedures influencing workplace violence between faculty members. Using principles from critical ethnography, the research was conducted within three schools of nursing at universities in Canada. Data collection included 29 semi-structured interviews with nursing faculty, key informants, and mute document review. Three major themes emerged: the academic apparatus, experiencing academia, and coping mechanisms. Nursing academic culture is divergent, exhibiting fierce competitiveness and elitism, intertwined with pockets of support and resilience. Faculty identified diverse personal and professional strategies employed in order to withstand the challenges. Need for change was expressed by some faculty and managers. These findings may support the efforts of faculty and management seeking transformation to a less competitive and elitist culture.

Connecting: The Parenting Experiences of Fathers of Children With Neurodisabilities

Aline Bogossian, *McGill University*

Lucyna M. Lach, *McGill University*

David Nicholas, *University of Calgary*

Ted McNeill, *Factor-Inwentash, University of Toronto*

Background and Objective(s): Parenting a child with a neurodisability (ND) can be a life-altering experience; however, much less is known about the unique experiences of fathers and the meanings that these experiences hold for them. The objective of this study was to explore the meanings fathers of children with NDs make of their parenting experience. **Study Design:** This study employed interpretive phenomenological analysis (IPA; Smith et al., 2009) to develop an understanding of the parenting experiences of fathers of children with NDs. IPA allows for in-depth exploration of participants' unique worlds and acknowledges the researchers' role in coconstructing those experiences. **Study Participants and Setting:** A purposive sample of 11 biological fathers of children and youth (mean age: 12.36; girls: 36%) with a range of NDs were recruited from pediatric health and rehabilitation centers in Alberta, Ontario, and Quebec. **Methods:** Data collection consisted of one to two in-depth, semistructured interviews (each 45–75 min in length) that were analyzed for themes that reflected the fathers' experiences of parenting their child. Efforts were made throughout the research process to ensure methodological rigor (i.e., reflexivity, sensitivity to context, and grounding findings in participant narratives). **Findings:** Fathers' evocative stories revealed their experience of forging emotional connections with their child, focusing their relational energies on understanding their child, learning from their child, and together, being in the world. **Conclusions/Significance:** Practice implications of this study include the importance of noticing and reinforcing fathers' emotional connection with their children, discussing parenting experiences with fathers, acknowledging fathers as resources in the family unit, and prioritizing fathers' information needs.

Use of the Critical Incident Technique (CIT) in Population Health Intervention Research: Lessons Learned

Achille Dadly Borvil, *Université de Montréal*

The Critical Incident Technique (CIT) is widely used in qualitative research. Since its conception by Flanagan (1954), variants have been used in different fields (Butterfield, 2005). Recently, Figueiro et al. (2017) introduced another variant of CIT, the Critical Event Card (CEC), a tool for analyzing the evolution of complex public health interventions using critical events. We used this tool to reconstruct and analyze the 4-year (2011–2015) deliberative processes involved in the revision of the policy framework of the “Initiative montréalaise”: an intersectoral social development intervention. In this article, we first present the methodological approach used to identify and

validate the critical events that serve as a basis for reconstructing and analyzing the intra- and intersectoral processes of negotiation and reconciliation around critical events, which eventually determined the consensus-based, revised framework. In a second step, we highlight lessons learned from applying this approach to a past, long-term, multiactor process, particularly with respect to (a) orienting research participants along the events' historical timeline during multistep data collection and (b) the researcher's stance relative to his object of study and his posture adopted to succeed in the data collection and validity. We conclude with methodological considerations when using the CEC to analyze complex public health interventions.

The Experiences of Nurses in Hemodialysis Units in a Tertiary Care Hospital Caring for Outpatients in Pain

Frances Fothergill Bourbonnais, *University of Ottawa*

Kelley Tousignant, *University of Ottawa*

Advanced chronic kidney disease is a major health problem, and hemodialysis is a life-sustaining therapy. Dialysis nurses have noted that some of their patients experience chronic pain from sources unrelated to the dialysis process. The purpose of this qualitative study was to describe nurses' experiences in caring for patients who were experiencing pain while receiving maintenance hemodialysis at outpatient units within a tertiary care institution. Semistructured interviews were conducted with seven nurses, and thematic analysis was used to analyze the data. Themes emerged related to the complexity of pain assessment and management in these patients. Nurses tried to figure out the pain as it could be related to dialysis or to comorbidities. They spoke of many patients being elderly and having arthritis and finding the chairs used for the treatment uncomfortable. Nipping it in the bud was their approach to help patients, but needing time was required to properly assess the pain. The need to look at the overall picture was essential due to multiple comorbidities and the complexity of administering analgesics to this population. Nurses learned how to advocate for patients in making the road smoother and this required working as a team. The nurses described needing a palliative approach to meet patient needs related to end-of-life care. Implications for practice, education, and research are brought forth.

Exploring the Experiences of Trainees in an Eating Disorder Prevention Program in Newfoundland and Labrador

Marlene Browne, *Memorial University of Newfoundland*

Pamela Ward, *Memorial University of Newfoundland*

Sarah Pickett, *Memorial University of Newfoundland*

Erin Cameron, *Memorial University of Newfoundland*

The Body Project is an eating disorder prevention program supported by a “train-the-trainer” implementation strategy.

This program has shown to be effective for improving body image concerns in young adults in the United States and now has made its way into Canada. In 2016, the Eating Disorder Foundation of Newfoundland and Labrador brought the program to Atlantic Canada and since then has conducted training workshops. The trainees are university students who are trained to conduct peer-led workshops in the university setting, along with high school teachers or guidance counselors who conduct workshops for high school students in the school setting. While there has been an abundance of quantitative research exploring the impact of this program on workshop participants, there has been no research conducted to date that explores the experiences of trainers. This presentation provides results from a qualitative study conducted to explore the experiences of people within the Body Project Canada training program. Using a feminist poststructural perspective, researchers collected data using focus groups and interviews to explore the trainees' perceptions of the training format and information sharing. Also explored were their notions of health, body, body image, and what, if any, influences the training session had on those notions.

Medical, Therapeutic, and Recreational Use of Marijuana Among Gay and Bisexual Male Emerging Adults Living With HIV/AIDS

Douglas Bruce, *DePaul University*
 Alida M. Bouris, *University of Chicago*
 Shannon Bowers, *DePaul University*
 Olivia Blocker, *University of Chicago*
 Soo Young Lee, *University of Chicago*
 John A. Schneider, *University of Chicago*
 Daniel H. Reirden, *University of Chicago*

Heavy marijuana use in the United States spikes during emerging adulthood with estimates of 4%–6% of 21- to 23-year-olds using daily, yet 25%–35% of gay/bisexual male emerging adults living with HIV have reported using daily. Previous findings have described an “overlap” between medical and recreational marijuana use among HIV-positive populations. In order to better understand the motives associated with medical and recreational dimensions of heavy marijuana use, we conducted semistructured interviews with 30 young gay/bisexual male emerging adults living with HIV/AIDS in Denver and Chicago. Interviews were audio recorded, transcribed, and coded by a diverse team of analysts. In addition to findings that mapped onto previously identified medical motives (relief from nausea, gastrointestinal distress, and pain) and recreational motives (socialization and relaxation), we identified several themes that straddled medical and recreational use in a domain we describe as therapeutic. Themes identified in this therapeutic domain of marijuana use include (a) enhanced mindfulness among individuals that promotes psychological adjustment to an HIV diagnosis, improved medical management, management of HIV-related stigma, and future orientation, (b) reflection processes that mitigate interpersonal conflict

and improve interpersonal communication, and (c) a social-therapeutic phenomena of marijuana use in which young persons with HIV reflect with one another that is both characterized by enhanced mindfulness and improved interpersonal communication. We discuss opportunities for therapeutic and medical management intervention with this population.

Developing the Identity of “Someone Who Does Self-Care”: A Grounded Theory Study of Health-Care Trainees

Jessica Campoli, *University of Saskatchewan*
 Jorden Cummings, *University of Saskatchewan*

Self-care is an ongoing professional necessity and ethical imperative that is integral for managing stress and preventing burnout in health-care professionals. However, there is a concerning gap between knowledge and action. Trainees often do not have effective coping strategies for dealing with the complex and novel training demands. They also face numerous, often practical, barriers to self-care. We conducted a grounded theory study aimed at understanding the process by which health-care trainees develop self-care practices and, related, where some health-care trainees might struggle to do so. We interviewed a heterogeneous sample of health-care trainees from multiple disciplines (e.g., pharmacy, nursing, physical therapy). Our results indicate that values, self-esteem, and informal/formal support systems play an integral role in self-care choices. Furthermore, in order for self-care practices to be consolidated and used in the face of challenges, trainees seem to need to develop the identity of someone who engages in self-care. Our results highlight the importance of individually tailored, value-driven, preventative self-care solutions. Recommendations for how to promote greater self-care and implications for interventions that can be used in professional training programs are discussed.

Youth Advisory Councils as Research Partners in ACCESS Open Minds: Coordinating Genuine Engagement

Eugenia Canas, *Western University*
 Srividya Iyer, *ACCESS Open Minds*
 Chantelle Mireault, *Douglas Hospital Research Centre*
 Rebecca Prince, *Chatham-Kent Health Alliance*

Our current mental health-care system is transforming to address youth mental health. National and provincial actors in health care acknowledge the impact of mental illness, calling for person- and family-centered care, and innovations in research, clinical practice, and service design that apply the perspectives of youth and other users of the system. We know little, however, about the work of including stakeholder knowledge to shape mental health services research. The ACCESS Open Minds (AOM) project is a Pan-Canadian mental health services research initiative that engages youth and family

members as advisors into all stages of research design, evaluation, and dissemination. Youth councils inform the project nationally and on some of its 12 research sites, shaping the research process as well as the culture of care in the communities where they live. This presentation describes the nature and impact of youth-engagement activities at the national and local levels of AOM. Drawing from the experiences of two youth engagement coordinators and using a qualitative, institutional-ethnographic approach presenters will describe the everyday work of engaging youth as stakeholders in service research and design. Key areas addressed by this presentation include visible and invisible dimensions of engagement work; competencies, practices, and challenges in engagement; and observed impacts of youth engagement both locally and on the national research project. Presenters will share strategies and lessons learned in engaging diverse populations of youth face-to-face and remotely, with broader implications for research projects undertaking this kind of participatory engagement of youth and/or other populations.

Young People Living With Epilepsy: Stress and Family Resilience

Judith Chew, *KK Women's and Children's Hospital*
John Carpenter, *University of Bristol*
Anne M. Haase, *University of Bristol*

Young people with chronic illnesses tend to have poorer psychosocial outcomes compared to their peers. Demands of living with a chronic medical condition create a range of stressors that may interfere with family interactions, which in turn affect young people's well-being. Thus, identifying and fostering resilience within families will be valuable in supporting these young people. A particular focus within this study, which is part of a larger mixed-methods study, was to examine the influence of family resilience on young people's adaptation. Semistructured interviews were conducted with 15 young people with epilepsy, aged between 13 and 16 years old, to understand how family processes supported their efforts and influenced strategies used to manage illness-related challenges and other developmental tasks. Findings from these interviews provided in-depth descriptions of stressful circumstances encountered and family processes. Key processes that mobilize resilience-building resources are situated within three primary domains of family functioning: organizational patterns, belief systems, and communication processes. Practitioners who support young people with chronic conditions, such as epilepsy, should consider interventions that strengthen these key family processes. In the area of organizational patterns, reinforcing family connectedness allows young people to turn to their families for support when experiencing demands and stress. It is also essential to explore young people's beliefs, helping them and their families construct a new sense of normality if necessary. Finally, sustaining open communication between family members, where differing views were acknowledged, was also found to be important in facilitating resilience.

Disability Research in Zambia: An Example of the Influence of Institutional Norms Constraining Critical-Emancipatory Ideals

Shaun Cleaver, *McGill University*
Stephanie Nixon, *University of Toronto*

Researchers operating from a critical-emancipatory paradigm approach research as a tactic to counter oppressive power relations. Despite this intent, research can unwittingly reproduce power relations, particularly as researchers tend to have greater societal privilege than those on/with whom they conduct research. We propose that the misalignment between researcher intentions of power sharing and research practices with unequal power relations is, at least at times, a product of institutional structures that researchers cannot easily ignore. Using the example of PhD dissertation research on disability in Zambia, we highlight ways in which critical-emancipatory research principles conflicted with institutional imperatives. In particular, we focus upon the intention to democratize the research process by privileging the perspectives and priorities of participants. Ultimately, through a series of researcher choices that instead privileged the successful and timely defense of the dissertation, the ideals of a democratic process were subverted. Through our example, we illuminate ways in which institutional structures and imperatives become accepted constraints on research practice. In identifying these subtle yet influential forces, we strive to contribute to the development of strategies that researchers can use to resist and counter the oppressive prevailing trends of institutions. From our assessment, the deployment of such resistive strategies is a necessary tactic for research practice in the critical-emancipatory paradigm.

Health Out of Foster Care: A Phenomenological Exploration of Seeking Health-Care Services After Aging Out of the U.S Foster-Care System

Jen Collins, *Texas Tech University Health Sciences Center*
Rosalinda Jimenez, *Texas Tech University Health Sciences Center*
Laura Thomas, *Texas Tech University Health Sciences Center*

Some adolescents in the United States who have been abused and/or neglected by caregivers are placed in permanent custody of the state and released at age 18 years of age, called "aging out," if not returned home or adopted. The quality of the care provided in this system, especially health care, has been a contentious issue, attracting both public and academic attention. Although much statistical evidence indicates poorer health outcomes among former foster youth as compared to nonfoster care peers, little experiential evidence exists to describe the phenomenon of seeking health-care services from the perspective of these former foster youth. In this research study, the researchers drew on the Phenomenology of Practice developed by Max van Manen (2014) to specifically query the phenomenon of seeking health-care services after foster care. We interviewed 13 former foster care youth

who aged out and aim to explore how they develop embodied, relational, and existential entanglement with health care in the discontinued structure. Lived experience descriptions were extracted from interview transcripts and analyzed under phenomenological themes. Former foster youth's experiences of health care were marked by being dismissed because of missing family history, being deprived of real choices by having no choice but to wait, becoming their own records keepers, relying on the kindness of strangers, and wanting to be seen as a patient—not a former foster kid. Health-care providers who integrate the findings into care delivery models will engage these youth with more understanding and sensitivities of ethical practice.

The Network in Intersectorial and Community Interventions as a Training Space to Professionals Dealing With Drug Addiction

Maria Ines Gandolfo Conceicao, *Universidade de Brasilia*
Marilia Mendes de Almeida, *Universidade de Brasilia*

This study had as an object the training of health professionals for working in networks to develop care actions for drug users. The objective of the research was to explore the contributions of the social networking analysis for the construction of continuing education strategies and study about the gaps and potentials for network actions in the attention for the drug users. The research field was the CRR-DF allocated in the School of Health Sciences/FEPECS/SES-DF. The investigation subjects were the students of the course offered in 2014, professionals, and partners of SUS. The theoretical basis of the study are the theories of social networks, the biopsychosocial model of health care, and the prospect of harm reduction, guided in the paradigm of complexity of Edgar Morin. The research instruments were a closed interview and a script for a discussion group. This study did a mapping of intersectorial and community network in the attention and care of the drug user at the Distrito Federal and metropolitan area, raised the main actions made, and held a group discussion. Through these procedures, the research demonstrated that the ARS has much to contribute to the development of training strategies for actions in intersectorial network. The ARS allowed identify the most important actors that influence harder the network, identify which partnerships need to be strengthened, the relational subgroups existing and allowed prepare specific training strategies for the identified relational dynamics, and the strategies to enable the territorial base of actions.

Exploring Contraceptive Experience to Understand Long-Acting Reversible Contraception (Non)Use Among a Cohort of Young, Australian Women

Jacqueline Coombe, *University of Newcastle*
Melissa L. Harris, *University of Newcastle*
Deborah Loxton, *University of Newcastle*

Over the past few years, interest in long-acting reversible contraception (LARC) as a way to reduce the rates of unintended

pregnancy has grown among both researchers and health service providers. Despite increasing advocacy for these highly effective and long-lasting methods, the rates of use in Australia, particularly among young women, remain low. Although research into this area is increasing, why young women choose to use less effective, short-term methods rather than LARC remains unclear. This presentation reports on qualitative data from a PhD thesis which aims to understand LARC (non-)use among a cohort of young Australian women. Drawing on both free-text data from a larger survey, as well as data from semi-structured interviews, this presentation provides insight into why women may or may not choose to use an LARC. By contextualizing women's experiences of using contraception, this presentation demonstrates the complexity of women's experiences, highlighting that changing needs, unclear or ambivalent feelings toward pregnancy, the normalization of the oral contraceptive pill, and a lack of interest and understanding about LARC underlie low rates of use. In addition, the findings suggest that there is a disconnect between what women value in a contraceptive method and what researchers and health service providers value, highlighting the importance of noncontraceptive effects. This research demonstrates the important role of qualitative research in providing voice to women's contraceptive experiences.

A Critical Interpretive Synthesis: Exploring How Older Adults Are Represented in Participatory Action Research

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Tanya Elizabeth Benjamin-Thomas, *University of Western Ontario*
Colleen McGrath, *University of Western Ontario*
Carri Hand, *University of Western Ontario*

To date, a plethora of studies on older adults have been conducted with the researcher positioned as “expert.” Participatory action research (PAR), however, is a methodology that promotes the inclusion of older adults as coresearchers in all phases of the research project including identifying a problem that matters to them and their community, selecting a research priority, and collaborating with the researcher in data collection, data analysis, and the dissemination of results. In this way, a PAR approach focuses on colearning as well as capacity building at both the individual and community level. Currently, there is a lack of scholarly attention on how PAR has been utilized with an older adult population. The purpose of this study, therefore, is to conduct a critical interpretive synthesis (CIS), set out by Dixon-Woods and colleagues, to evaluate the use of PAR with older adults as well as examine how power is shared between researchers and older adults to reveal any ageist or ableist assumptions. A systematic search to identify relevant articles will be carried out using various databases. Key questions guiding this critical analysis include how are the older adults meaningfully involved within each phase of the research project? and how was power shared between older adults and researchers? A CIS moves beyond appraising and

synthesizing the research findings, toward critically questioning the dominant tendencies within a particular topic of research. As such, the findings of this study have the potential to stimulate further uptake of PAR research with an older adult population.

“Have No Regrets”: Parents’ Experiences and Developmental Tasks in Pregnancy With a Lethal Fetal Diagnosis

Denise Cote-Arsenault, *University of North Carolina Greensboro*
Erin Denney-Koelsch, *University of Rochester Medical Center*

Background: Prenatal testing is now routine in pregnancy, and in 2% of pregnancies, lethal fetal diagnoses are made. For those parents who choose to continue the pregnancy, their experience is unquestionably altered once they learn that their baby is not healthy. Little is known about how the psychological and processes in pregnancy are altered. **Methods:** This hermeneutic phenomenological study of 16 mothers and 14 spouses/partners sought to learn the parent experiences and developmental tasks across pregnancy. Interviews were conducted with mothers and fathers during pregnancy and after the baby’s birth and death. Data analysis was iterative, through a minimum of two cycles of coding, theme identification, within- and cross-case analysis. **Results:** Parents’ goal was to “Have No Regrets” when all was done. Five stages of pregnancy (prediagnosis, learning diagnosis, living with diagnosis, birth and death, and postdeath) and seven developmental tasks of pregnancy (navigating relationships, comprehending implications of the condition, revising goals of pregnancy, making the most of time with baby, preparing for birth and inevitable death, advocating for baby with integrity, and adjusting to life in the absence of baby) were identified. Prognostic certainty was found to be highly influential in parents’ progression through developmental tasks. **Conclusion:** The developmental framework can be useful to providers who care for families, especially in perinatal palliative care. Matching care with the stage and developmental tasks of these families may lead to greater parent satisfaction and improved care.

It’s for Us. And It’s for the Community: The SHARP Walking Program for African-American Brain Health

Raina Croff, *Oregon Health & Science University*
Miya Walker, *Portland State University*
Edline Francois, *Oregon Health & Science University*

African Americans are twice as likely to develop Alzheimer’s disease and other dementias due to high rates of chronic conditions like diabetes, obesity, and hypertension. Physical activity and social engagement may improve/sustain cognitive health as we age. However, gentrification in Portland, Oregon’s historically African American neighborhoods, has decreased older African Americans’ motivation to engage in

neighborhood walking and social opportunities. The Sharing History through Active Reminiscence and Photo-imagery (SHARP) Pilot Program is part of the Healthy Brain Research Network of the Centers for Disease Control and Prevention. SHARP integrated historical images of local African American culture into walking routes to motivate six triads of African Americans aged 55 and over to engage in neighborhood walking and social engagement over 6 months. Conversational reminiscence was recorded to create a digital oral history archive that will be integrated into community learning sessions bridging community memory to individual memory and brain health. Surveys show the program increased physical activity and social engagement and improved mood. Focus group data show the walking program’s culturally celebratory images and conversation prompts sustained interest, while recording conversations for community education curated a sense of purpose and meaning because it served individual and community health needs. Walking through gentrified neighborhoods made participants feel seen when gentrification has made them feel invisible, helped them deal emotionally with neighborhood changes, and improved brain health awareness. The SHARP program offers insight into designing health programming that goes beyond cultural relevancy to be culturally celebratory while serving individual and community health.

“It Made It Real”: Applying Rural Suicide Prevention Gatekeeper Training in Everyday Life

Kate Davies, *University of Newcastle*
Fiona Livingstone, *University of Newcastle*
Angela Booth, *University of Newcastle*

Gatekeeper suicide prevention programs are advocated as an important strategy within integrated approaches to suicide prevention in Australia, training key community members with skills to recognize and respond to people at risk of suicide. In rural Australia, people tend to experience worse mental health outcomes than their urban counterparts and there are often limited specialist support services available. Rural gatekeeper training programs offer challenges and opportunities for improving health outcomes, but little is known about what happens beyond the training room. Good SPACE is a rural Australian gatekeeper suicide prevention program, with quantitative evidence linking the program to improvements in participants’ suicide stigma and literacy. This study examined more deeply the experience of applying suicide prevention skills and knowledge in everyday lives in a rural setting. A series of qualitative interviews with Good SPACE workshop participants ($n = 30$), 3 months after their participation in training, revealed that most respondents had not had an intervention with a person at risk of suicide. However, respondents found that skills related to nonjudgmental discussion of suicide and holistic health, translated into new approaches for their own health

and self-care, and gave them cause to reflect on their attitudes and approaches to people experiencing hardship. Maintaining the momentum for changes experienced after training was difficult for people who returned to workplaces or homes where their newly gained knowledge was not recognized. Some respondents also reported that while the training changed them, it did not change the limited access to health and well-being services in their communities.

Changes in Health Professionals' Attitudes, Beliefs, and Father-Inclusive Practices After Implementation of the Father-Friendly Initiative

Francine deMontigny, *Université du Québec en Outaouais*

Christine Gervais, *Université du Québec en Outaouais*

Danae Lariviere Bastien, *Université du Québec en Outaouais*

Diane Dubeau, *Université du Québec en Outaouais*

Background: For the past 40 years, scholars have been studying the development of the father's role in the family. It is well known that fathers' involvement benefits children's cognitive and social development and contributes to both parents' well-being. Recent research has shown that social and professional support can be protective factors for father involvement. The Father Friendly Initiative within the Family (FFIF) program was developed in 2010 to empower health professionals to support fathers' involvement, detect fathers' mental health problems, and ultimately prevent child abuse and neglect. It has been implemented in four regions of Quebec (Canada) from 2012 to 2017. **Objectives:** This presentation will describe the effects of the FFIF on professionals' beliefs and practices toward fathers. **Methods:** The evaluation phase was carried out through 39 qualitative interviews with health professionals. Interviews were transcribed and analyses were performed with NVivo. **Results:** The effects of the FFIF on professionals are found at three levels of transformation: (a) beliefs, (b) conception of their own role, and (c) interventions and pertain to three themes: (1) barriers experienced by fathers, (2) importance of father involvement, and (3) differences between fathers and mothers. Professionals became aware of the issues related to those themes and this contributed, firstly, to a transformation of their beliefs. Secondly, they began a personal reflection, which led to a transformation of the conception of their own role. They realized the role they could play in reducing barriers faced by fathers and promoting father involvement. Thirdly, they transformed their interventions to reach fathers, encourage their participation, and treat them fairly. **Conclusion:** Professionals are adopting father-friendly beliefs and behaviors after participating in this innovative program. The discussion will explore implications for father-inclusive family practices, family research, education, and policy development in support of fathers' involvement.

Aligning Collaborative and Transformative Research With Local Ways of Knowing and Being

Joyce Duckles, *University of Rochester*

George Moses, *North East Area Development*

Our collaborative, ethnographic research began in 2012 when community activists from the Cedarwood neighborhood approached the university to work together to gather their own evidence to inform the transformation of their community. They were frustrated with being researched and with having others plan initiatives for their neighborhood. To drive sustainable change in Cedarwood, we have become coresearchers, complements, and coauthors intentionally using our data, practices, and writing to understand the processes of activism while challenging the structures sustaining disparities and constraining pathways of transformation. Collaborative research in urban contexts presents many challenges. In a predominantly African American community, tensions with Eurocentric research practices have led us to historical and local ways of knowing and being to inform our iterative processes of researching, implementing, and writing. In this presentation, we share how our current analysis has led us to the Afrocentric principle of Self-Determination ("Naming Ourselves") as a sensitizing concept. In our research, we build on the determination of community members to pose their questions and own their data. In our praxis, we intentionally coconstruct multiple pathways to engagement and activism. In our writing and dissemination, we recognize that "he who has the pen, owns the history," and thus, we create dialogic spaces and novel strategies to pass around the pen. We share our practices that bridge and value the multiple identities and epistemologies of our team and propose that this pluralism, grounded firmly in goals of activism and change, frames valuable ways of engaging with one another as researchers, practitioners, and authors.

Supporting Participation of Marginalized People in Community-Based Participatory Action Research: Challenges and Struggles

Sophie Dupéré, *L'Université du Québec*

Lucie Gelineau, *L'Université du Québec*

In the context of a community-based participatory action research about food security and the fight against poverty, which took place from 2011 to 2014 in the province of Québec and involved 25 members (two academics, four women living in poverty, eight practitioners, four students, and a community member) which met on a monthly basis, we documented our strategies and tools used to better involve people living in poverty in the various stages of our research project. After briefly presenting the context of the project, the objectives, and methodology, we will discuss some of the main challenges we encountered to sustain the authentic participation of the most marginalized people, beyond the alibi role they are too often confined to. We will discuss about power relations, recognition

of lay knowledge, and practices such as handicraft, retention of participants, participation related expenses, and institutional requirements. Reflecting upon the strengths and limits of our strategies and tools, we will present some of our key lessons: the importance of open dialogue where differences of opinion are permitted, reflexivity, capacity building of team members for authentic participation, necessity to draw boundaries, to establish safeguards as well as to recognize pugnacity as a key behavior for success! We will also show how the mixed expertises of our team, notably expertise of people living poverty, were crucial to mobilize participants and adapt our methods. Conclusion will be drawn for future participatory action research projects.

Methodological Challenges Faced Doing Qualitative Research With Socially Vulnerable People

Sophie Dupéré, *Université de Sherbrooke*
Christine Loignon, *Université de Sherbrooke*
Lynda Benhadj, *Université de Sherbrooke*

A number of methodological challenges confront research teams working with socially vulnerable groups in the field; however, few detailed articles are available to inform other studies. The aim of this presentation is to outline these challenges, more specifically those encountered during data collection in the context of a qualitative multisite-focused ethnographic study, taking place in three cities (Québec, Montréal, and Ottawa) in Canada. The main objective of our research project was to understand the experiences and perceptions of socially vulnerable persons using innovative health care in community clinics. To meet our objectives, we conducted semistructured interviews with patients and informal interviews with the clinics' managers, clinicians, and members of the medical team. Observations *in situ* allowed us to describe daily health-care professionals' practices and patients' navigation issues and routines. Our presentation will focus on the challenges regarding rapport building with the clinics, sampling, and recruitment of people living in poverty and socially excluded. The debates that occurred among the research team during the data collection will be presented. The multifaceted approach and strategies used will also be discussed as well as their strengths and limits. In conclusion, we will argue that the challenges encountered by qualitative researchers studying vulnerable groups can be overcome by collaborative efforts and ongoing dialogue between researchers and the participants involved in the study. Conclusion will be drawn for future qualitative research projects.

Intentional Uprootedness: Women Temporary Agricultural Workers in Canada

Kathryn Edmunds, *University of Windsor*
Helene Berman, *Western University*

The concept of uprootedness refers to dislocation in different contexts of displacement and settlement. The purpose of this

research was to discover women temporary agricultural workers' experiences of health during lengthy and recurring uprootedness from their homes and families within intersecting gendered, political, and economic structures. Using critical-feminist ethnography, methods included interviews with 20 women from Mexico, the Philippines, and Jamaica, employed in two Canadian temporary worker programs. Participants strongly considered their employment as a necessary maternal responsibility and caring sacrifice to support their families. Because of the women's precarious immigration and work status, their repeated separations occurred in an environment of systematic and continuous uncertainty. Experiences of health, home, and community were lived through a dialectic of connection and isolation. Migrant experiences of uprootedness are often essentialized and framed as primarily affecting individuals. However, circular and recurrent relocation changes everyone—not only the people migrating, but the families and communities left behind, as well as the communities to which workers travel. Fixed dichotomies of being designated as either citizens or temporary workers create and sustain categories of exclusion that inhibit public engagement. Looking beyond these dichotomies means recognizing and exploring the consequences of current structures and systems. Listening to how people create meaning within displacement and, in collaboration with participants, promoting their stories can lead to a much richer, layered, and multidimensional understanding of similar and diverse migration pathways including the contexts of power that surround and are embedded in local, national, and international discourses.

Decision Making in the Occupational Therapy Evaluation Process: A Grounded Theory Study

Judy Beck Ericksen, *Elizabethtown College*
Adelyn Enders, *Elizabethtown College*
Elise Starkey, *Elizabethtown College*
Megan Ziff, *Elizabethtown College*

Evaluation lays the foundation for the occupational therapy process and informs how therapists address client needs. Because of this, choosing appropriate assessment tools, that is, those that are consistent with practitioner and client aims and values, is key to providing effective services to clients. While there is ample literature describing the influence of internal and external factors on a therapist's clinical reasoning, there is little that explicitly relates these factors to assessment in a way that illuminates this decision-making process. For this pilot study, Charmaz's grounded theory approach framed the overarching methodology as well as the completion of data analysis. Sixteen practitioners from a variety of settings, including early intervention, outpatient rehabilitation, inpatient acute care, schools, mental health, and long-term care, were interviewed. Participants described the evaluation process and selection of assessment tools as multifaceted. Four factors that influenced the selection of assessment tools emerged: the client

characteristics, possible tools, setting characteristics, and therapist influencers. A preliminary theory is proposed that captures therapists' perceived ability to find congruence among factors and then adjust and modify their approach based on the client's performance and characteristics. The researchers made an intentional decision to explore a wide range of settings; there is evidence suggesting that while factors vary across settings, the process may be similar. Additional interviews are planned to further explore these initial findings.

From Survival to Healthy Aging: Couples Living With Late Side Effects After Removal of the Prostate

Lotte Evron, *Metropolitan University College*
Gitte Wind, *Metropolitan University College*

Research shows that patients' and spouses' narratives about their everyday lives before, during, and after a diagnosis of chronic illness may help health-care professionals to improve treatment and enhance quality of life for patients and their spouses. From a narrative perspective, this study investigates everyday life and togetherness of eight men and their spouses (51–75 years old) before, during, and after surgery for prostate cancer. Twenty-four dyadic in-depth interviews (three by eight) were carried out 2–4 months (with the couple) and 6–10 months (with the patient and partner separately) after surgery. The interviews lasted 2–5 hr. Throughout the narratives, the patients and the spouses built their mutual and individual lives focusing on their relationship and strived to return to their usual everyday life. Within 3–6 months, the couples went from “survival” where the diagnosis dominated to “well-being” where healthy aging/lifestyle dominated. All eight couples led a relatively healthy lifestyle before surgery but increased their healthy life style significantly after surgery. However, the couples did not mention their rather radical changes in everyday life such as exercising for 12 hr weekly, excluding meat in their diet or taking high doses of C-vitamins/ginger/chili as a change in everyday life. There were differences in coping styles between men and women in everyday life with regard to the late side effects. These findings highlight the importance of helping couples to cope with late side effects differently (individually?) over time. Understanding of the couples different needs over time and need for individual communication may increase the quality of treatment and quality of life for couples.

A Values-Based Framework for Designing Serious Games

Manuela Ferrari, *McMaster University*
Suzanne Archie, *McMaster University*
Nick Bush, *Moonray Studios*
Dan Clark, *Moonray Studios*

Over the last 10 years, several serious video games on health-related topics have been developed. However, the game

industry lacks clear standards on how sensitive topics related to illness and sufferings were portrayed. In the mental health context, many commercial video games perpetuate “madness” stereotypes (e.g., insanity, violence). This article presents a framework for serious game design, which aims at identifying core values that can inform the creation of serious games about the various delineations of mental illness. The framework was created as part of a participatory project that engaged youth and video game industry in the creation of a commercial video game about psychosis: *Debris*—a 3-D game produced by Moonray Studios. Five youths (age 17–19), the founder and project manager of Moonray Studios, and the academic researcher met over 6 months. Seven focus groups were implemented to discuss video game elements (e.g., game characters, story), video game experiences, and messages around psychosis/mental illness. Each focus group was recorded and transcribed. Thematic analysis was used to identify themes and mapping technique, which generated the framework used for exploring the relationship between themes. A framework for creating a video game was constructed with the following elements: gamer values, mental health video game values, and video game learning objectives. The discussion between the youth and game developers captured by the framework influenced the game mechanisms of *Debris*. The proposed framework can offer guidelines for game developers interested in creating serious games on mental illness.

Process of Creating a Digital Database for Secondary Qualitative Data Analysis: The Digital Archive of Psychosis Narratives

Manuela Ferrari, *Douglas Mental Health University Institute*
Srividya Narayanan Iyer, *Douglas Mental Health University Institute*
Ashok Malla, *McGill University*

Secondary data analysis refers to the usage of existing data in order to investigate research questions other than the primary ones for which the data were originally gathered. Important research questions can be answered efficiently to some extent using existing data; however, the practice of reanalyzing existing qualitative data and/or sharing these data between researchers is often a source of debate and disagreement. Over the years, a specialized treatment for psychosis located in Montreal has collected more than 400 text narratives of young people with early experiences of psychosis and their journey to mental health care. These text narratives, between two to four pages long, were created as part of the Course of Onset and Relapse Schedule interview—a semistructured interview conducted by researchers with the young person. This interview systemically explored different stages in life (e.g., childhood, adolescence) and gathered further information on family relationships, peer relationship, schooling/early work experiences, and life events (e.g., migrations, violence, trauma). In this presentation, we (1) describe the process of creating a digital database of more than 200 text narratives how text narratives were organized and

categorized for secondary data analysis, (2) describe how this database can answer new research questions and/or can generate new subjects of inquiry that can be used to design future research studies, and (3) reflect on the possible theoretical and methodological limitations of secondary data analysis. We will discuss our experience in the context of other qualitative data repositories (e.g., the United States, Europe) exploring theoretical, methodological, and ethical potentials and challenges.

The Dance of Authority: Interactions in Interprofessional Team Meetings

Stephanie Fox, *Université de Montréal*

Mariline Comeau-Vallée, *Université de Québec*

Medical dominance is well-documented in the literature on collaboration, but the concept of authority in interprofessional interactions has not been extensively studied. We examine the nuanced negotiation of authority performance and its collective accomplishment by both physicians and other professionals. Guided by an interactionist approach, we asked how does authority get negotiated in interprofessional team meetings? Drawing on data from two ethnographic case studies of team meetings in different clinical contexts (acute care, $n = 23$, and outpatient mental health, $n = 10$), we analyzed team interactions for practices by which authority is performed. We identified three main themes: establishing a climate, making knowledge claims, and enacting interactional obligations and rights. The practices associated with these themes reveal that authority can and does take different forms in interaction. Our findings show how fluid authority can be in these contexts, for instance, how, over the course of the same discussion, authority can move from being incarnated solely by the physician to being shared by others. Authority is not limited to a unilateral exercise of power or to major clinical decision-making but inheres in interactional activities as subtle as taking the conversational floor, orienting team discussion, and commenting on others' contributions. This research expands the conceptualization of authority in the scholarship on medical dominance and recognizes the potential influence of other professionals in clinical meetings.

Taking People Back to the Future: The Role of Hermeneutic Temporality in Participatory Research and Public Engagement

Julie Fréchette, *McGill University Ingram School of Nursing*

Marianne Sofronas, *McGill University Ingram School of Nursing*

Marjorie Montreuil, *McGill University Ingram School of Nursing*

Many qualitative studies aim to capture, understand, and interpret the experience of time, but how does temporality interface with participatory approaches? This presentation aims to review the philosophical underpinnings of temporality by exploring the development of this concept in

phenomenology and hermeneutics and to elaborate on the role of temporality in participatory research and public engagement. The writings of Heidegger and Gadamer will serve as a springboard from which to better understand later thinkers such as Merleau-Ponty, Ricoeur, and Taylor. Human beings are situated in time with their past experiences throwing them in the present moment, which is never devoid of a projection into the future (waiting toward). Humans interpret their experiences with this conception of time as a standpoint. Inspiring citizens to engage in research can be greatly enhanced by taking a second look at temporality. At the onset of participatory research, potential partners can be guided in bringing to the fore how the research ties with their past, present, and future. Considering the hermeneutic conception of time allows the research team, in the larger sense, to integrate a continual process of interpretation that not only promotes the commitment of partners but also supports the cocreation of lasting meaning. Examples from nursing research will be presented to illustrate ways in which hermeneutical foundations intersect with participatory research approaches.

Phenomenology BOOT CAMP!

Julie Fréchette, *McGill University*

Marianne Sofronas, *McGill University*

Marjorie Montreuil, *McGill University*

Are you ready to be phenomenologically charged? This methodological boot camp will trace the philosophical underpinnings of experience-based research approaches by reviewing the development of phenomenology and hermeneutics as critiques of empiricism, philosophical movements, and research methodologies. Concepts reviewed will include lifeworld, bracketing, being/Dasein, temporality, thrownness, language, and dialogue. The works of foundational thinkers within phenomenologic and hermeneutic traditions, Heidegger and Gadamer, will serve as a springboard to interpret the ideas of more contemporary phenomenologists such as Ricoeur, Merleau-Ponty, and Taylor. Application of these concepts to qualitative research will also be discussed with specific examples from nursing research. This presentation will allow participants to enjoy an overview of interpretive phenomenology and how it can inform participatory approaches with a touch of humor and no sweating guaranteed.

The Experience of Kangaroo Holding: A Meta-Synthesis of Qualitative Research Reports

Anitra Frederick, *University of Texas Health Science Center at Houston*

Kangaroo care is the holding of a neonate against the caregiver's bare chest shortly after birth. This practice has foundations in nature, and vast research has shown physiologic

benefits for mother and neonate. The practice of kangaroo care is recommended by the World Health Organization and is frequent hospital policy for its known benefits. Qualitative inquiry into the phenomena is present in the literature but sparse. These studies explore kangaroo holding in a variety of settings with the mother or father and their neonate of varying ages. A qualitative meta-synthesis was conducted to achieve two goals: (1) amalgamation of qualitative findings for deeper understanding including appropriate application to practice and (2) identification of gaps in knowing for future exploration. Qualitative content analysis was chosen to synthesize identified studies meeting the inclusion criteria. Study findings were coded, organized, and summarized by similarity and then placed under thematic headings. Data collection and analysis has been examined with colleagues for consensus. The included studies were conducted in six different countries, highlighting the importance and interest of this topic to a diverse community. Themes that emerged from the meta-synthesis revolve around the intense connectedness felt by the parent toward the neonate and the power held by the health-care provider, as gatekeeper, in creating an environment for this experience to be shared. The poster presentation will include greater detail in findings and identified gaps in knowing for future study. The author welcomes discussion with colleagues on the topic and potential applications to practice.

What Is This “Impact” We Seek to Measure? Toward a More Meaningful Impact-Tracking Strategy for Health Professions Education Research

Farah Friesen, *University of Toronto*

Stella Ng, *University of Toronto*

Lindsay Baker, *University of Toronto*

Amy Dionne, *University of Toronto*

To acquire and maintain funding, health professions education (HPE) researchers face increasing pressure to demonstrate impact. But what is impact? This question should be critically examined, as the ways we define impact affect the indicators used to “measure” impact. Indicators form the reward system that shape and constrain researchers’ focus and endeavors. Traditionally, quantitative indicators are measured (e.g., citation analysis). Yet, education is also interested in complex social impacts, which are often challenging to represent through quantitative data. In an effort to more fully represent HPE researchers’ impacts, we integrated relevant indicators from several tools (e.g., Kuruvilla’s Research Impact Framework, Becker Model, Aguinis’s Pluralistic Conceptualization). We introduce novel ideas such as gray metrics and impact stories to develop a meaningful approach to tracking impact in the HPE context, which may have broader applications. The intention is not to produce a recipe or set up new, burdensome ways for researchers to “prove their worth” but to create and encourage alternative ways of thinking about impact.

Exploring the Use of Mobile Information and Communication Technologies by People With Mood Disorders, and Their Health and Social Care Professionals

Hamish Fulford, *University of the West of Scotland*

Thilo Kroll, *University College Dublin*

Steve MacGillivray, *University of Dundee*

Linda McSwiggan, *University of Dundee*

Constructivist grounded theory methodology was used to generate a substantive theory, underpinned by a theoretical framework, that explained how people with mood disorders, and their health and social care professionals, used mobile information and communications technology (mICT). Twenty-six patients and 10 health and social care professionals were interviewed before theoretical saturation was achieved. The core category that emerged from data, forming theory, was “centrality through praxis of interconnectivity.” People with mood disorders were using their mICTs to stay central within their online and offline worlds. Their devices become central in terms of their importance and their feelings of attachment toward them. Centrality was achieved through the “praxis of interconnectivity,” the act of managing their interconnectedness through their use of mICTs. Through managing their continuums of interconnectivity, this facilitated people to “manage their needs,” “outsource their needs,” and attend to their “disconnection of needs.” People engage in continuums of centrality to meet their needs irrespective of whether these needs were primarily, biological, psychological, or social. Positioning on continuums were not fixed but rather changed as people engaged in their activities of daily living. Their centrality flexed via the praxis of interconnectivity, from remaining inward looking within the intrapersonal with limited mICT use, to achieving centrality across socioecological domains, and increased use of their mICTs. Both people recovering from mood disorders and health- and social care professionals can use the findings of this study to help make sense of, and harness, the mICTs they use in daily life and practice.

HIV Vulnerability and Risk Assessment of Migrant Female College Students

Vaishali Gautam, *UCMS*

A. K. Sharma, *UCMS*

S.K. Bhasin, *UCMS*

Migrant population is a recognized risk group for HIV infection. Female migrants have been world over found to be at higher risk of HIV infection, but evidence is limited. This study was conducted to explore HIV/AIDS related vulnerability and risk of a novel group that is migrant female college students. Mixed-method approach (i.e., quantitative and qualitative exploratory method) was used. For quantitative aspect, a randomly selected group of 100 female migrant students were recruited and administered semiclosed questionnaire assessing their HIV/AIDS related vulnerability and risk. Respondents

with self-reported high-risk sexual behavior were subjected to in-depth interviews (qualitative aspect) with the purpose to identify the factors that increased their vulnerability and risk. The 21% of the respondents had inadequate HIV/AIDS-related knowledge, mean age of sexual initiation was 18.7 years, and 10% of the respondents showed high-risk sexual behavior as none used condom consistently. Statistically significant association was observed between respondent's high-risk behavior and having friends who were sexually exposed ($p < .005$) and also with respondent's partner's current place of residence ($p < .001$). From in-depth interviews, push factors like greater opportunities, peer pressure, and pull factor like coerced sexual intercourse lead to high-risk sexual behavior. In addition, behavioral factors like inability to negotiate condom use, embarrassment in purchasing condoms, and poor self-perceived risk further increased the respondent's vulnerability to acquire HIV infection. Keeping in mind that in India, migrant female students comprises a sizable number; hence, we conclude that migrant female college students are vulnerable, therefore requires focus to further measure their HIV vulnerability and risk and develop reduction measures.

Participatory Cartography: A Powerful Tool for Collaborative Analysis Involving Marginalized Citizens

Lucie Gelineau, *Université du Québec, Rimouski*
Sophie Dupéré, *Université Laval Vaatavec (PAR Team)*

The objective of this presentation is to describe the use and adaptation of participatory cartography as a key element for collective qualitative analysis in a community-based participatory research project. We used the participatory cartography within focus groups to fully analyze, with people living in poverty and socially excluded, their food environments and food access strategies. Cartography allowed us to collectively examine how access to food and services is in fact socially differentiated and highlight disparities of freedom, wealth, empowerment, and rights. It allowed us to explore economic, social, and political causes and impacts. This qualitative research took place in three research sites (urban, semiurban, and rural areas) in the province of Québec. Data were collected through collaborative cartography strategy and, then, transferred within a geomatic database for further analysis as well as valorisation of results. During this communication, we will describe the participatory cartography process as such, reflect on how this approach and tools were developed notably with four women living in poverty, and show how their crucial inputs helped us adapt the method. Like others, we found the dialogue produced around the mapping exercise was richer than the maps themselves. We will share the examples of its outputs in our renewed understanding of food access, social environment, and living territories. We will finally discuss how it allowed collective analysis, an often overlook key issue of the qualitative research process.

Collaborative Techniques to Engender Talk About Pregnancy, Health, and Well-Being: Dyad Sandboxing With Mothers in Wales, UK

Aimee Grant, *Cardiff University*
Melanie Morgan, *Cardiff University*
Dawn Mannay, *Cardiff University*
Dunla Gallagher, *Cardiff University*

Within the UK, there is concern regarding health behaviors in pregnancy, such as smoking and drinking alcohol. Many current interventions produce disappointing results, which may be because of a failure to understand the wider context of women's lives. To engender a more nuanced understanding of maternal experiences, we undertook three interviews each with 10 pregnant women who lived in deprived areas and who claimed welfare benefits. We used a range of visual methods: (i) timeline facilitated life history interviews, (ii) collaging facilitated interviews, and (iii) collaborative sandboxing. Sandboxing is a practice of providing the participant with a tray of sand and a range of figures and everyday objects, with which to make a representation of their experiences. This article focuses on the usefulness of collaborative sandboxing as a reflexive tool of data production, where both participants and researchers made representations of their maternal experiences. Participants and researchers used the sand to construct either a representation of a specific event or a more general feeling relating to social encounters. The dyad approach was adopted to reduce participant feelings of being observed when creating their sandscape. It also enabled participants to guide the course of the interview. Despite different forms of engagement with the activity, questions were answered which we would not have thought to ask in a standard interview. This article explores the process of collaborative sandboxing, highlighting the practicalities, opportunities, and limitations of this approach.

It's Not About the Timeline: The Use of Creative and Visual Methods to Increase Participant Control During Interviews About Arthritis and Family Planning

Aimee Grant, *Cardiff University*
Bethan Pell, *Cardiff University*
Denitza Williams, *Cardiff University*
Rhiannon Phillips, *Cardiff University on behalf of the STAR Family Study Team*

In recent decades, the use of visual and creative techniques in interview studies has expanded considerably. One explicit aim is to give participants greater control in the interview encounter in order to coproduce data. In this article, we describe our experiences of undertaking research using a "timeline" template with women with rheumatic diseases (such as arthritis and Lupus) who were considering starting a family, were pregnant, or who had recently had a baby ($n = 22$). Prior to interviews, women were sent a timeline template which asked them to

consider the impact of their disease on family planning at key time points including diagnosis, preconception, and pregnancy. However, we emphasized that women did not need to complete a timeline and should not feel constrained by our template. Twelve participants prepared some notes or a timeline, and seven of these were shared with the research team. Drawing on extracts from interview transcripts and the researchers' reflective diaries, we aim to provide reassurance that these creative techniques may be used as part of elicitation interviews that aim to encourage the participant to control the direction of the interview with minimal analysis on the timeline itself. However, the wider aspects of our approach to data production, such as a gentle and friendly approach, reassurance that the participants did not have to complete the preinterview task, and incentives were an important element of reducing the power imbalance. Through our reflexive account, we discuss the practicalities of defining the "ethos" of the study and ensuring the research team have a shared understanding which runs through the study.

An Aesthetic of Relationality: Unsettling Conceptions of Traditional Inquiry and Inviting Public Engagement With Research

Julia Gray, *Bloorview Research Institute*

Qualitative health researchers are increasingly turning to the arts as ways to translate research into real world contexts and engage members of the public with research in more meaningful and inspiring ways. There is emerging evidence of the efficacy of the use of the arts as part of research with audiences. However, questions have emerged about the legitimacy and rigor of arts-based research and the ways it might fit or be defined within scientific epistemological expectations of knowledge production and legitimacy; discussions are often framed as how arts-based research might gain academic recognition within the sciences. What is overlooked in these discussions is the ways that artist-researchers, understood as those undertaking a scholarly exploration primarily through artistic form(s), engage in their practices as legitimate unto themselves. Additionally overlooked is the ways these arts practices might be connected to audience engagement. Through this presentation, I will bring conversations together between artist-researchers and qualitative health researchers to open up questions about what constitutes legitimate forms of knowledge production. Drawing on examples from the research-informed play "Cracked: new light on dementia," I will highlight the ways artist-researchers imaginatively and foolishly (or vulnerably bravely) engage their embodiment throughout their processes as part of an aesthetic of relationality. I will conclude by considering how an aesthetic of relationality, as an aesthetic space within which the embodied interpretive work of artist-researchers is extended into spatial, relational contexts, both unsettle conceptions of traditional inquiry and invites public engagement with research.

The Experiences of Parents of Pediatric Patients With Acute Lymphoblastic Leukemia, Two Months After Completion of Treatment

Andrea Greenblatt, *University of Toronto*

Barbara Muskat, *Hospital for Sick Children*

This project aimed to understand the experiences, emotional states, and support needs of parents of pediatric patients with acute lymphoblastic leukemia (ALL), 2 months after completion of treatment. Seventeen parents from the Leukemia/Lymphoma Program of a large Canadian urban pediatric cancer center shared the experiences of treatment completion in semi-structured interviews. An interpretive descriptive approach was applied, and the data were analyzed using computer-based data management and analysis software, N-Vivo 10. The following methods were used throughout the analysis process: (a) prolonged engagement: the research team had extensive experience working with parents of children with ALL; (b) negative case analysis: Inconsistent cases were specifically sought out; (c) peer debriefing: Numerous discussions were held to explore and examine emerging themes, with transcripts being reviewed by several team members. Team consensus around codes took significant time, review, and team dialogue; and (d) Thick description: Generated themes included rich descriptive accounts of participant experiences. Three primary themes emerged from the data: parents' experiences of juxtaposing emotions (i.e., feelings of simultaneous relief along with uncertainty), a return to normalcy following completion of treatment, and changes in the relationship with the health-care team. A fear of relapse of their child's leukemia permeated the majority of parents' narratives, connecting all three primary themes. Rich understanding of the complex experiences of parents during this transitional period has led to practice change around end of treatment procedures. Specifically, greater consideration has been applied to the supportive needs of families as the familiar routines associated with treatment ends.

Biotechnology and Reconstructing the Self Through Genetic Health Markers

Katherine Gregory, *CUNY/New York City College of Technology*

New commercial technologies, like direct-to-consumer (DTC) genetic testing kits, increasingly promise personalized genetic information on demand. With access to our individual genome, the author and her informants have reaped contestable genetic knowledge that repositions concepts of ethnic/racial ancestry, "preillness" state, and structures of meaning assigned a "core" genetic identity. Using autoethnographic, in-depth interviews, and data scraping methodologies as well as visual analysis mapping of the process of discovery, this article aims at understanding how the social construction of identity assigned to health markers and the body, a locus still salient in a scientific landscape in which biotechnology and big data increasingly trump all other forms of knowledge production, is understood

through a feminist phenomenological lens. By examining the discriminating process of uncovering new self-narratives, errors in vital records, the author comes to a new genealogical awareness: Whether the results play a preventive role in maintaining health or they are simply selectively chosen and integrated into a meta self-concept, ethical, social, and health diagnostic issues are challenged and a new social construction emerges from this research.

A Grounded Theory Inquiry Into Crying in Women Dealing With the Emotional Stress of Personal Crisis

Mary Griffith, *University of Tennessee*

The belief that crying leads to healing is so widely held and of such long-standing that many health-care professionals including nurses, physicians, psychiatrists, and psychologists accept it as fact even though there is little substantiating scientific evidence. Crying is commonly believed to be an essential factor in restoring mind-body equilibrium after physical and/or emotional trauma has been experienced. If, as has been hypothesized by many scientists and health-care practitioners, emotional crying is a biopsychosocial healing modality, then specifics of its therapeutic praxis, including limitations and ambiguities, should be incorporated into nursing education and practice. In this grounded theory study, the meaning and functions imparted to crying by women who cried after experiencing stress in a variety of crisis situations and settings were revealed in semistructured interviews. Analysis of these data permitted realization of the Tipping Point Theory of Crying, a new grounded theory explanatory of the stress-related crying process. This theory shares similarities with other theories of crying, but its empirical perspective offers a fresh, more subtly nuanced appraisal of how crying is indispensable to a processual sequence that involves stress relief concomitant with the attenuation of crying, restoration of cognitive clarity that leads to accepting and adapting to a reenvisioned reality inclusive of the crisis event, and a new state of psychophysiological equilibrium necessary for self-preservation and “getting back to life.” Included in study results were findings that further illuminated how women deal with crying in different social settings, why crying during sad movies is qualitatively different than the emotional crying associated with stressors personally endured, why women in our culture try hard to control crying, why women cry alone, how women define different types of crying, how emotional crying at noncrisis levels may be amenable to self-regulation, and how crying in response to overwhelming emotional upset can be empowering. Analysis of the data provided by study participants revealed numerous potential investigative opportunities that are likely to lead to the advancement of holistic nursing teaching and practice. In addition to the theoretical, clinical, and educational implications of study findings, opportunities for additional research, both quantitative and qualitative, are elaborated.

Got Milk?: Childcare Programs' Implementation of Healthy Beverage Policy

Jori N. Hall, *The University of Georgia*

Caree J. Cotwright, *The University of Georgia*

Nearly 20% of American children are overweight or obese before they enter kindergarten. A major contributor to high rates of obesity, particularly among minority and low-income children, is sugar-sweetened beverages. The Child and Adult Care Food Program (CACFP), a federal program, reimburses childcare programs serving low-income children and aims to increase access to healthy beverages. Because the CACFP has the potential to impact the diets of millions of young children, understanding how the policy regulations are translated into practice is of great importance. Accordingly, the present study uses a mixed-methods design to explore the status of childcare program beverage practices in a southeastern state. Childcare program providers across the state completed an online survey ($N = 597$) to assess the level of implementation of beverage best practices. Findings from the survey indicate programs perceive implementing the CACFP at high levels with limited challenges. This micro-oral presentation will discuss the 6 focus group interviews with childcare providers and 20 individual interviews with program directors currently underway. Interview responses are being coded using the constant comparative method in NVivo10 by a team of trained coders. Preliminary qualitative findings corroborate survey findings, suggesting CACFP regulations are being implemented with fidelity. Further analysis will provide an in-depth understanding of how childcare provider beliefs, resources, and barriers affect compliance with beverage policies.

Health-Care Professionals as Parental Advisors in the Danish Welfare State

Helle Haslund, *Aalborg University*

Active citizenship oriented toward optimizing health is a dominant discourse in Denmark and affects how parenthood is perceived and practised. Consequently, Danish health-care professionals monitor and guide parents in practises and choices in spite of lack of evidence on multiple topics.

An extensive 1.5-year ethnographic fieldwork with Danish parents to late preterm children in their homes using participant observations (138 times) and interviews (21) examined how health-care professionals interacted with parents during the first 1.5 year of the child's life and how health-care information was used by parents. The study shows that the advice given orally and in written form by health-care professionals is not accepted and acted on without reflections and hesitations. Health-care professional knowledge is, however, translated and transformed into everyday life through multiple negotiations on the Internet and also through lay groups on the Internet, in peer groups, friends, and family. The results point out that health-care authority is challenged and compliance is complex, which calls for new ways of collaboration

and communication that take parents critique and reflective use of information into account.

Understanding the Relationship Between Psychological Well-Being and Preventive Care Use in Midlife African-American Women

Vida Henderson, *University of Illinois School of Public Health*
 Jessica Madrigal, *University of Illinois School of Public Health*
 Arden Handler, *University of Illinois School of Public Health*

Background: Preventive care is underutilized in the United States, resulting in increased morbidity, lost lives, and inefficient use of health-care dollars. African American women (AAW) are particularly at risk of deleterious health outcomes that might be mitigated through increased preventive care use. Psychological well-being (PWB) may provide an important target for interventions aimed at increasing timely utilization of preventive services. **Objective:** To explore midlife (aged 40–64) AAW’s perceptions and experiences of PWB and how these experiences affect their utilization of well-woman visits (WWVs) and preventive care services. **Methods:** A mixed-methods study was conducted with women from the Service Employees International Union—Healthcare Illinois Indiana headquartered in Chicago. Women ($n = 124$) participated in an online survey that assessed their use of preventive services and WWVs, barriers and facilitators of use, and women’s degree of PWB. One-on-one semistructured interviews ($n = 19$) were conducted with a subsample of participants that assessed the same constructs. Data were collected from May 2016 to October 2016. **Results:** Qualitative findings showed that community violence was a major threat to women’s well-being and that spiritual practices, helping others, and positive reframing of challenges greatly contributed to women’s well-being. Access to affordable insurance and positive provider relationships facilitated women’s use of preventive care. Influenza vaccine was the most misunderstood and least utilized preventive service. **Conclusion:** A better understanding of factors that impact the relationship between midlife AAW’s PWB and use of preventive services may inform strategies to increase utilization, which will in turn positively impact disease and disability as this group of at-risk women age.

Situating Gender in Narratives of Resilience: An Analysis of Youth Narratives About Distress and Coping

Carla T. Hilario, *Simon Fraser University*
 Cara Ng, *Simon Fraser University*
 Joy Johnson, *Simon Fraser University*

Contemporary definitions of resilience describe it as the capacity of young people to navigate their way to resources that support their health and well-being, amid contexts of

significant adversity. While the study of resilience has yielded nuanced analysis and understandings of resilience in relation to cultural contexts, there has been limited study of how gender relations and norms shape young people’s resilience and the ways these dynamics intersect with place. The aim of this presentation is to share emerging findings from a narrative analysis of qualitative research data from the Researching Adolescent Distress and Resilience study. The study was conducted in three communities in British Columbia, Canada, with young people aged 13–18 years. Exploring youth narratives in one of the research sites—a small northern community in the province—a critical gender lens is applied to examine the extent to which young people’s narratives about distress and coping strategies in their everyday lives are shaped by gendered norms, expectations, and relations. We also explore the ways these findings have implications for public health approaches that account for and are responsive to the unique needs of youth populations across the gender continuum. We argue for a strong engagement with critical gender theories in qualitative health research.

The Politics and Optics of Engagement in Participatory Video: Subjectivities, Power, and Representation in Qualitative Health Research With Immigrant and Refugee Young Men

Carla T. Hilario, *University of British Columbia*

Collaborative approaches using video have been held up as promising methodologies to explore the perspectives of vulnerable groups and to build community capacity. The aim of this presentation is to highlight the politics and optics of engagement in participatory video in relation to subjectivities, power, and representation. Drawing on data from a mental health promotion study with immigrant and refugee young men, a reflexive analysis was undertaken to examine subjectivities in the research process, power and empowerment with respect to collaboration, issues of representation and the politics of knowledge, and the underlying assumptions about the methodology’s emancipatory potential. This study provides an example of an iterative participatory video process in which multiple narratives and subjectivities were layered in a video that the young men, in the role of collaborators, created and tailored not for those traditionally “in power” but for themselves and for other young people.

Factors That Foster Resilience Following Traumatic Childhood Experiences

Monica Hinton, *University of Calgary*

In Canada, the Committee on Sexual Offences Against Children and Youths report that, among adult Canadians, 53% of women and 31% of men are sexually abused as children. Studies suggest that exposure to childhood sexual abuse

(CSA) is associated with a wide range of adverse consequences including depression, anxiety, substance abuse, attempted suicide, deliberate self-harm, and a range of other adverse psychological outcomes. There is research, however, that has examined the factors that distinguish individuals exposed to childhood sexual abuse who develop adjustment issues, from those children exposed to CSA who do not. A range of factors, including personality traits, family characteristics, and community influences, have been identified as important determinants of resiliency following exposure to CSA. The purpose of my own qualitative grounded theory research was to uncover what participants believed fostered their resiliency. Self-identified resilient volunteers were interviewed, data were analyzed using grounded theory, and the chosen central phenomenon was the perception that the participants' childhood sexual abuse was traumatic. Strategies used by the research participants to address this phenomenon included enlisting important individuals/pets, spirituality, and regulating the traumatic experience. Participants regulated their trauma through strategies including humor, self-preservation, imagination, and "unhealthy" behaviors. The results indicate that there are degrees of resiliency; resiliency is a process and each participant moved beyond periods of using unhealthy strategies in regulating their experience.

Trans Owned Trans Research

Mateo Huevo, *Athabasca University*

Professionals across disciplines are becoming increasingly aware of the need to provide appropriate services to transgender populations. However, it is difficult to know how to do so when policies and institutions provide irregular structural supports, and there are general biases and omissions in our academic literature and education. With these barriers to providing trans-affirmative care, how do we set ourselves up for success? This presentation will center on learnings taken from The Trans Community Says Project, a community-based participatory research project with transgender groups in Alberta. The principal investigator of the project will provide a brief overview of the broader context of trans-affirmative mental health in Canada. He will then discuss key learnings about insider-outsider research collaboration with transgender communities highlighted from the Project. The audience will discuss how knowledge creation and translation can be implemented with trans communities.

The Wondering and Puzzling Involved in a Narrative Inquiry Approach

Margaret Hughes, *Ara Institute of Canterbury*
Ray Kirk, *Canterbury University*
Alison Dixon, *Canterbury University*

The aim of this presentation is to describe the lessons learned from the narrative inquiry approach chosen to investigate how first- and second-level nurses communicate with each other during delegation interactions. Choosing a methodology that

is congruent with your own worldview is the number one top tip for a successful and enjoyable research project. For this research project, the requirement to honor relational ethics and the three commonplaces of time, sociality, and place added to the rigor and believability of the research and met my own views about a robust research process. As a method, narrative inquiry provided a vehicle to capture nurses' storied experiences of their delegation interactions. Nurses tell stories each shift as progress notes, shift handovers, and patient education sessions. This strength became a challenge as nurses often felt self-conscious talking about themselves and found it difficult to tell their story unfettered from beginning to end. This meant that a new way of presenting the nurse's stories had to be found. A narrative inquiry approach made visible the different nurse's perspectives between and across their shared stories, as well as the unique and different stories that emerged as the narrative plot of the delegation strategies they used and the choices they made. Accessing 36 nurse participants' stories led to the challenge of privileging and honoring each storied experience. My experience of narrative inquiry is that it is empowering and ethical and that both the participants and the researcher are changed by the narrative process.

Telling Tales: Using a Narrative Inquiry Approach to Explore Nurses' Perceptions of Delegation Interactions

Margaret Hughes, *Ara Institute of Canterbury*
Ray Kirk, *Canterbury University*
Alison Dixon, *Canterbury University*

How nurses communicate with each other during delegation interactions can impact on retaining nurses in the workplace and patient safety. The purpose of this study was to explore the way nurses communicated during delegation interactions, their perceptions of delegation as a professional competency, and the barriers and enablers to good delegation communication interactions.

Exploratory semistructured interviews with prompt suggestions were offered to a purposive sample of 36 nurses across a variety of workplace settings including in-patient and community placements. Experienced and inexperienced first- and second-level nurses who were registered with Nursing Council and therefore held a current practising certificate were invited to participate in this narrative inquiry study. The major patterns that emerged from this study included the need to communicate well, to work in a team as well as a team, and the need for delegation skills such as leadership and assessment skills. While there were similarities between first- and second-level nurses' perceptions of the delegation interactions they had been involved in, each nurse had a unique and different strategy for meeting delegation as a required professional competency. Some of these findings support previous findings on delegation, but many of the findings encapsulated in their storied experiences are new. The findings suggest that there is a need for more education about how to "do" delegation, and how

nursing education, and nursing management and leadership, can enable “good” delegation interactions so that the first- and second-level nurses’ professional obligation to delegate, or be delegated to, and ensure patient safety and dignity is supported.

“I Thought I Was Controlling a Temporary Problem”: Exploring Patient Experience Along the Pathway to Diagnosis for Oesophageal and Gastric Cancer

Elka Humphrys, *University of Cambridge*

Jenni Burt

Greg Rubin

Fiona M. Walter, *University of Cambridge*

In 2012, there were over 1.4 million cases of oesophageal and gastric (OG) cancer diagnosed worldwide and more than 1.1 million deaths. Increasing symptom awareness and understanding, encouraging prompt help-seeking, and facilitating timely referral are priorities for improving outcomes. This mixed-methods study aimed to explore the pathway to diagnosis of OG cancer in the UK from a patient’s perspective. Patients aged 18 and over and newly diagnosed with OG cancer at two hospitals in the East and Northeast of England were consecutively approached over a 14-month period. Participants completed a study questionnaire and were purposively sampled by location, gender, age, and cancer for semistructured, face-to-face in-depth interviews conducted within 10 weeks of diagnosis to explore symptom experience, help-seeking, and aspects of health literacy. Ninety-six participants completed the questionnaire, and 26 interviews were conducted between May 2016 and July 2017 (13 East England, 18 males, age 55–88, 15 oesophageal cancer). Early analysis highlights the importance of understanding the social context of eating when exploring appraisal and help-seeking for upper gastrointestinal symptoms. Most participants did not expect cancer as a reason for their symptoms, describing themselves as healthy despite experiencing multiple symptoms and often making significant dietary changes to manage them. Help-seeking was prompted when symptoms accumulated or were difficult to control and particularly when they became noticeable when eating socially. This is the first study to explore the “time to diagnosis” for OG cancer from a patient’s perspective, with findings providing important insights for the development of targeted awareness campaigns and strategies enhancing GP exploration about symptoms of OG cancer.

Doing Qualitative Research in the Context of Emergency Medicine: Methodological Considerations

Aman Hussain, *University of Winnipeg*

Anthony Rossi, *Queensland University of Technology*

Steven Rynne, *University of Queensland*

The rationale for this study was a gainful attempt to investigate the learning processes of medical residents and practicing

attending physicians in the context of emergency medicine. Specifically, there was interest examining the lived experience of becoming a practicing emergency medicine physician. With this in mind, research questions were developed to determine the nature of learning in the residency workplace. Using a hermeneutic phenomenological theoretical framework informed by Heidegger (1962), semistructured interviews were conducted with 18 emergency medicine residents ($n = 18$) and 15 ($n = 15$) practising emergency medicine attending physicians. In addition to the interviews, five ($n = 5$) observations were conducted of the participants in the emergency department to get a better understanding of the combined learning environment and workplace. These observations were helpful for developing an understanding of the learning environment and workplace of the residents and attending physicians. Vignettes were written to illustrate several of the findings and contextualize the lived experience of the participants. One of the main methodological findings of this study was that many of the residents “wanted” to share their stories. Participating was perceived to be important and a service to the profession; that is, to speak about the residency process so that it could be continuously improved upon and made better for those that follow. Additional methodological considerations involve the importance of being invited into a learning community as an outsider (but of the field of learning) in order to interact with young practitioners who wanted their voices heard.

Anticipating Needs at End of Life in Narratives Related by People Living With HIV/AIDS in Appalachia

Sadie Hutson, *University of Tennessee-Knoxville*

Joanne Hall, *University of Tennessee-Knoxville*

Frankie West, *University of Tennessee-Knoxville*

In the United States, Southern states bear the burden of the highest incidence of HIV and comparatively have the lowest survival rate for Persons living with HIV / AIDS (PLWHA). Culturally competent research is needed to address the advanced care planning and end-of-life (EOL) health-care needs of PLWHA. Experientially based knowledge is needed regarding the EOL needs of PLWHA in the rural southeastern United States. As part of a mixed-methods investigation determining EOL needs in Southern Appalachia, we analyzed narratives embedded in interviews of eight selected participants living in Appalachian areas of Tennessee and Alabama. Narratives were analyzed syntactically and semantically, noting turning points. The primary finding was that stigma and shrinking circles of social support for PLWHA combined to create a sense of solitariness. Narratives were fraught with tensions and paradoxes. In the Bible Belt, religiously based stigma against HIV is pronounced, reflecting stereotypes about sexual behavior and illicit drug use. Distances are long, yet news travels quickly. Community rejection, even shunning, can occur as well as breaks in family bonds. Receiving a diagnosis of HIV was a key turning point that realigned many social

relationships, work careers, and health trajectories. We concluded that the discussion that occurred surrounding a new HIV diagnosis was key to future health-care planning including openness to plan EOL. Narratives underscore that anticipating EOL situations is stressful. Stigma, whether experienced, anticipated, or internalized, is traumatic; there is psychological as well as illness-related stress in anticipating EOL for PLWHA.

Exploring Applications of Interpretive Description and Its Use in Nursing Research: A Scoping Review

Ashley Hyde, *University of Alberta*
Jennifer Bell, *University of Alberta*
Sarah Stahlke, *University of Alberta*
Maria Mayan, *University of Alberta*

Interpretive description (ID) is an emerging method that is claimed to be distinctly grounded in nursing epistemology. Since its inception, there has been an increased uptake of ID in nursing research. Given its expansion and its potential influence on nursing inquiry, it is vital to understand more about how this method is used and to evaluate its contributions to and shortcomings for nursing research. Thorne and colleagues (1997) claim that ID allows nursing researchers to depart from traditional methods while retaining both their practice orientation and the methodological integrity of their scholarship. Yet, when compared to other established qualitative methods, ID is methodologically underspecified and is purposefully distanced from methods and theories of other disciplines. This can be philosophically problematic and, practically speaking, offers little methodological guidance for would-be ID researchers. These concerns led us to conduct a scoping review of research using Thorne's ID to examine the methodological practices in use and link these to the stated purposes of the method and to the goals of nursing research. Specifically, we examined published examples of ID research projects in nursing to see what kinds of questions are being asked, what data collection and analysis strategies are used, how the findings are presented, whether theory is incorporated, and what, if any, methodological insights are shared. The goal of the review was to examine the actual usage of ID and map its methodological features, with the goal of informing and guiding high-quality future research that is relevant to nursing's epistemologies and purposes.

Interviewing Children With Home Mechanical Ventilation: Privileges and Challenges

Åsa Israelsson-Skogsberg, *University of Borås*
Berit Lindahl, *University of Borås*
Lena Hedén, *University of Borås*

Research that focuses on children living with home mechanical ventilation (HMV) and their own voices and perspective is

sparse. Developments in medical technology, care, and treatment have increased the survival of children with serious illnesses or injuries. This means that a raising numbers of technology-assisted children can live their lives in their own homes. Children with HMV are a part of this unique population. The underlying medical diagnosis varies and may cause severe functional limitations, for example, difficulties to breathe, walk, eat, swallow, and in some cases, talk. Ventilator support may be required either during sleep or over 24 hr invasively (with tracheostomy) or noninvasively (with a face mask). The aim is to present experiences from interviewing children living with faltering voices and communication problems related to ventilator treatment. Nine interviews with children (age range 7–20 years) with HMV were conducted. Photovoice was used to supplement the data collection process. Challenges with interviewing will be presented, such as individually tailoring the interview sessions to each person's wishes, having a parent or a personal care assistant present at the interviews, and the privileges in being welcome to share a moment in the child's daily life. Data were analyzed using an inductive and interpretive approach to qualitative content analysis. The comprehensive, careful, and slow data analysis revealed that the parent's voice was sometimes a part of the voice of the child and had to be handled as one voice. The child's voice itself was not strong enough to conduct a long conversation.

Family Involvement in the Lives and Treatment of Youth With First-Episode Psychosis in Chennai, India and Montreal, Canada: A Mixed-Methods Study

Srividya Iyer, *Douglas Mental Health University Institute*
Megan Pope, *Douglas Mental Health University Institute*
Padmavati Ramachandran, *Schizophrenia Research Foundation*
Ashok Malla, *McGill University*

The outcomes of schizophrenia vary across sociocultural contexts, yet it is unclear why. Compared to Canada, family factors may contribute to better outcomes in India. Our mixed-methods study seeks to understand the role of families in Chennai, India and Montreal, Canada, the factors influencing family involvement and other outcomes and perceptions of the family's role among key stakeholders. In the quantitative arm, patients, families, and treatment providers from two first-episode psychosis (FEP) programs in Chennai and Montreal completed questionnaires assessing family involvement in treatment, trust in medical professionals/establishments, and so on. Across sites, most families were involved in treatment; however, significantly more patients in Chennai reported family involvement in treatment. Chennai families were more likely to accompany patients to appointments and give medication and appointment reminders. In the qualitative arm, focus groups with families at both sites explored definitions/views of "family," the perceived role of families in the context of FEP, and the morality/motivations underlying caregiving. Families "being there" for their ill relative was an important theme

across sites. While Chennai families largely described their involvement in caregiving as executing treatment providers' recommendations, Montreal families tended to describe their role as complementary to, but distinct from, the treatment team's. Different moral languages around caregiving emerged, with greater emphasis on prescriptive roles and duty in Chennai and personal choice in Montreal. These findings highlight the important role families play in supporting a loved one with FEP and yield insights on factors that may explain how sociocultural contexts influence family involvement in the treatment of persons with psychosis.

The Lived Embodiment of Women With Female Genital Cutting (FGC)

Danielle Jacobson, *University of Toronto*
Robin Mason, *University of Toronto*
Gillian Einstein, *University of Toronto*

Female genital circumcision/mutilation/cutting (FGC) is practiced in many African countries, and the immediate adverse health outcomes are well-documented. Less well understood are the long-term consequences and their impact on the everyday lives of the women who have immigrated to the West. We have hypothesized that FGC leads to neural rewiring and potentially to a chronic pain condition that would be experienced in their everyday lives. In order to better understand how the original experience of FGC affects the lived experiences of Canadian-Somali women, we used qualitative interviews to learn about their daily lives, pain, and pleasure in the context of their FGC. The interviews revealed busy and active women engaging in rich family, work, and social lives. Their discussion of bodily sensation was situated within their life experiences with the following themes emerging: laughter, silence, "something you have to pass," the normal body, and my body. These themes worked at normalizing their bodies in a context that views them as different. Throughout the narratives of normalization are also indications of bodily pleasure and pain including, but also beyond, the vulvar region. While they had pain, they did not view themselves as a person in pain. Since many cultures believe that pain is normal in women's lives, these findings may have wider ramifications of our understanding of gender, health, and pain.

A Qualitative Investigation of Positive, Transformational Change Following a First Episode of Psychosis

Gerald Jordan, *Douglas Mental Health University Institute*
Tovah Cowan, *Douglas Mental Health University Institute*
Ashok Malla, *McGill University*
Srividya Iyer, *McGill University*

A first episode of psychosis (FEP) is arguably the most severe mental disorder emerging during youth. However, FEP may also present an opportunity for positive, transformational change, an area that has received very little attention. Given this gap, I will attempt to answer two questions: (1) what

positive, transformational changes do youth experience following FEP and (2) what factors or processes do youth feel facilitate such changes? A qualitative descriptive design guided the project. Data were gathered through semistructured interviews conducted with 12 purposefully sampled youth with FEP receiving early intervention services at two time points. Interviews were transcribed verbatim and subject to thematic analysis using inductive and deductive methods. Youth described how FEP led them to feel stronger, more grounded, and more authentic in their interactions and lifestyle choices; gain self-awareness, maturity, and purpose in life; develop stronger, wiser connections with others; and give back in the form of community engagement. Experiencing positive change was achieved through a process of negotiating adversity that was present prior to one's FEP; experiencing a sense of healing; capitalizing on one's strengths, passions, and interests; being supported by others; receiving services from empathetic clinicians, especially psychotherapists; and drawing on lessons derived from FEP when dealing with future challenges. These findings provide an evidence base that early intervention services can draw from in order to better provide positive, hopeful, strengths-based services to youth experiencing FEP. The findings also validate the experiences of youth who have experienced positive change as a result of their experience of FEP.

Post-Surgical Cliff after Bariatric Surgery: Accounts of Patients and their Health-Care Practitioners

Sandra Jumbe, *Queen Mary University of London*
Jane Meyrick, *University of the West of England*
Diana Harcourt, *University of the West of England*

The superiority of bariatric surgery for improving medical outcomes in severely obese individuals when compared to other weight loss interventions remains undisputed. However, knowledge about the psychological impact of the procedure on people's lives is limited. Systematic reviews indicate persisting disordered psychological well-being after surgery compared to control groups especially longer term, suggesting need for postoperative psychological support and assessment. Research literature also infers limited knowledge regarding the postoperative patient's lived experience of bariatric surgery. This may form a barrier in health-care practitioners' understanding of these patients' ongoing needs. For this reason, 10 individuals who had bariatric surgery 2 or more years ago and 8 bariatric surgery practitioners were recruited within UK public hospital settings and individually interviewed by the researcher to capture their accounts of the postoperative bariatric surgery experience. Concordance between the two groups was explored to gauge awareness of patients' subsequent health needs. Thematic analysis of transcribed interviews elicited a key finding around "postsurgical cliffs in patient care" within a heavily structured service. Participants reported some unmet needs, namely, psychological aftercare to facilitate adjustment following drastic weight loss and excess skin, acceptance of their

nonobese self and perceived prejudice. The impact of contrasting views of success between patients and practitioners on postoperative care within the service context was highlighted. Overall, bariatric surgery is a great weight loss catalyst for severe obesity. However, the lack of psychological aftercare may threaten long-term health outcomes. The influence of public engagement, particularly the process of interview development and future recommendations, is discussed.

Perceptions of Nutrition: Exploring Factors That May Impact Learning Outcomes

May Kamleh, *University of Guelph*

Deep Khosa, *University of Guelph*

Elizabeth Stone, *University of Guelph*

Educational health strategies incorporating the views of target participants have improved the likelihood of success. Extant research shows veterinary and medical professionals face increasing challenges in discussing nutrition with clients, also noting professional nutrition education as vital for effective communication. The aim of this study was to elicit student veterinarians' nutrition-related perceptions and nutrition information-seeking behaviors at the time of entering veterinary school and to identify attitudes that may influence their learning outcomes for nutrition education. Nineteen veterinary students from a Canadian university were purposively recruited for four in-depth focus group discussions. Participants were prompted with questions about the social and environmental barriers to healthy eating, confidence in seeking nutrition information, and effective delivery of nutrition education. Verbatim transcripts were analyzed with thematic content analysis using NVivo 10. Students reported to be influenced by individual factors (e.g., time and convenience), their social networks (e.g., family), physical environment (e.g., cost of food products), and macro environment (e.g., contradictory messages in the media). Main barriers perceived to learning nutrition included seeking credible sources of information and lower perceived emphasis on nutrition training in professional programs. Sources of information included primarily the web, family members and to a lesser extent, health-care professionals. Given the overall liberal access to nutrition information, our data support the importance of qualitative research in capturing professional students' own perceptions on nutrition that may impact nutrition education and suggest this as an important curricular consideration in preparing them for their roles as health-care providers.

Advancing Systems of Care for Disadvantaged Patients (Developing an Education Strategy)

Emilia Kangasjarvi, *University of Toronto*

Lindsay Baker, *University of Toronto*

Stella Ng, *University of Toronto*

Recent calls in medical education and health care have prioritized caring for disadvantaged patient populations (DPP).

Education has been highlighted as a key mechanism to move toward this goal. However, in order to develop effective education strategies, we must first better understand the concept of DPP. Using an interpretive qualitative approach informed by principles of critical discourse analysis, we studied the notion of caring for DPP at an inner-city teaching and research hospital. We conducted focus groups with trainees and staff representing health disciplines, nursing, medicine, and patients experiencing disadvantage as identified in the hospital's strategic plan: mental health and addiction; vulnerable housing or homelessness; aboriginal, immigrant, or refugee status; sexual orientation; gender identity; and patients falling outside these categories. We identified three main assumed "truths" that operate in the discourse of DPP: (1) disadvantaged patients require care above and beyond the norm, (2) the system is to blame for failures in serving disadvantaged patients, and (3) labeling patients is problematic and stigmatizing. In response to these discursive truths, patients wanted to be seen as valuable human beings, first and foremost, and not as a burden or category. Patients appreciated that the DPP discourse opened up better access to care, however felt differentiated from the norm, and made to feel "othered." As a result, they felt they were not accessing the same level of care in terms of compassion and respect. Based on our findings and based on extant education theory and science, we recommend three educational approaches to help improve care for patients experiencing disadvantage.

Designing and Conducting Observational Research on the Move Within High-Tech Environments

Jonas Karlsson, *University of Borås*

Isabell Fridh, *University of Borås*

Thomas Eriksson, *University of Borås*

This presentation will focus on the experiences of performing research within complex high-tech environments and contexts while on the move, using participant observation combined with video recording and hermeneutical analysis.

In recent years, interhospital transfers within intensive care have increased dramatically. These transfers are considered as complex and high risk due to critical illness and care taking place in a mobile environment across high-tech contexts. Research regarding transfers of intensive care patients is limited and almost entirely consisting of quantitative research methodologies. There is a significant lack of research with creative and holistic qualitative approaches focusing on the patient and their family members' unique situation within the transfer process. Eight intensive care unit to unit transfers carried out by ambulance were included in the data collection process, with the aim to explore the patient's situation and perspective during transfers. This complex data collection required the researcher to follow the patient throughout the transfer, performing participant observation and video recording. This involved the researcher's presence from the transfer

preparations, during the ambulance transport and the handover at the new unit. The data collection resulted in 7 hr and 23 min of video material and field notes, which finally was analyzed using a hermeneutic approach. This presentation will offer unique insights regarding participant observation and video recording within high-tech environments and contexts. The presentation will further discuss pros and cons with this design as well as problematize key issues and ethical considerations.

Families' Experiences Living With Acquired Brain Injury: A Narrative Inquiry Study

Jane Karpa, *University of Manitoba*
Wanda Chernomas, *University of Manitoba*
Kerstin Roger, *University of Manitoba*
Tuula Heinonen, *University of Manitoba*

Notoriously known as the “silent epidemic,” acquired brain injury (ABI) has reached worldwide epidemic proportions. While ABIs are manifested in individuals, families’ lives are dramatically affected by ABIs. Although research furnishes valuable insights on how an individual views family life, the science on ABI and families is limited in examining the group family perspective of their experiences living with ABI. Underpinned by ambiguous loss theory, the purpose of this qualitative narrative study was to examine families’ experiences living with ABI. The research question was: How do families make sense of their experiences living with ABI? This oral presentation will include a discussion of the research methods and highlight findings. This study used a research approach that included both the affected individual family member and the family together as a family group. Research methods for this study included (1) within a western Canadian province, purposeful sampling of individuals with ABI living in the community and their self-defined family members, (2) transactional level data collection through conjoint in-depth face-to-face interviews also informed by ethnographic methods, and (3) within-case and across-case analysis procedures, resulting in individual family unit interpretive case summaries and a master interpretive narrative. Rigor was ensured through the criteria of trustworthiness: credibility, dependability, confirmability, transferability, and authenticity. The results from this study will provide deeper understandings of families’ ABI experiences and inform health-care research, education, and clinical practice, contributing toward a health-care model that identifies “family” as a unit of care.

The Experiences of Mothers of Adolescents Who Misuse Substances

Masoumeh Katouziyan, *Ottawa Hospital*
Amanda Vandyk, *University of Ottawa*
Wendy Peterson, *University of Ottawa*
J. Craig Phillips, *University of Ottawa*

When a family encounters the problem of adolescent substance misuse, the burden of managing it often falls primarily on the

mother. This research explored the experiences of mothers of adolescents who misuse substances and was conducted in two phases. Phase 1 was a systematic qualitative evidence synthesis of qualitative studies on the experiences of mothers of adolescents who misused substances. Eleven qualitative studies met inclusion criteria and were reviewed using conventional content analysis to create a narrative synthesis of themes and categories. New categories regarding mothers’ experiences emerged: (1) I love you and we can talk no matter what; (2) So this is really happening... My kid’s on drugs; (3) What have I done?; (4) My family is shattered: (a) I can’t believe what you’re doing, (b) I can’t face this, and (c) I’ve lost my baby; and (5) It’s not my addiction. Phase 2 was a qualitative study that described four mothers’ experiences of parenting an adolescent who misused drugs. Semistructured interviews and thematic analysis were used to describe mothers’ experiences, which were represented in the following categories: (1) recognition, (2) punishment/surveillance, (3) negative emotions, (4) relationships, (5) escalating effects, (6) strategies, and (7) home, a safe place. The findings from this research contribute to our understanding of the everyday lives and struggles that mothers face with their adolescents’ substance misuse. Future research is needed to develop clinical interventions to more effectively meet the needs of families affected by adolescent substance misuse.

Acknowledging Limited Resources, Are Futility Decisions at End of Life Appropriate in Terms of Bioethical, Legal, and Policy Considerations?

Agnes Kaufman, *Creighton University*

Mankind has mastered innovations that can only be described as miraculous. Who could have predicted that advances in medical science would allow an individual to be maintained with artificial hydration and mechanical support for an unspecified period of time? As Kasman (2004) stated, “modern medicine has made it feasible to support human life for an indeterminate period...” which has necessitated the “difficult legal and moral discussions concerning medical futility and transitions from aggressive treatment to comfort care.” One might question whether we as a society have a genuine right to question if or when all medical and technological aid should be applicable to patient care? Should all patients in all circumstances have the option to avail themselves of any and all medical resources until and unless they so choose? Global researchers are relentlessly focused on obviating the restrictive and painful effects of pathogens—disease processes with the ultimate goal of maintaining and lengthening lives. The painstaking struggles of these tireless pioneers do not come without substantial cost. With the health-care systems in many Westernized countries being stretched to the limits, the occasional indiscriminate application of innovative scientific methodologies has come under scrutiny. When one potentially proposes to ration the current use of available medical technology indiscriminately, then it is worthwhile to examine when it is

fitting and proper to justify the need to portion resources. This article will address whether there is validation from a bioethical, legal, and policy point of view, for triaging medical resources in cases of medical futility. The case will be presented in the context of medical futility using the case of Hassan Rasouli in Toronto, Ontario, at the Sunnybrook Health Sciences Centre.

Improving Health and Safety for Immigrant South-Asian women Survivors of Intimate Partner Violence

Harjit Kaur, *Monash University*

Wendy Cross, *Monash University*

Virginia Plummer, *Monash University*

Medical, police, and community frontline responders are often the first point of entry for many immigrant women experiencing intimate partner violence. According to Statistics Canada's research data, only 22% of domestic violence cases come to the attention of police and an even smaller number of women disclose abuse when seeking medical attention. Immigrant South-Asian women face multiple vulnerabilities impacted by migration, lack of social and financial support, and system barriers when seeking health-care and police services in order to remain safe, healthy, and alive. These are global issues and not limited to particular cultures or religions and have clinical, psychological, emotional, financial, sexual, physical health, and safety consequences. It remains critical that the experiences of immigrant South-Asian women be understood within the violence against women framework and its interconnection to domestic violence in order to serve as a key exemplar for improving their health and safety. A multimethod qualitative approach employed by this study includes focus groups with women survivors and interviews with service providers and stakeholders. A culturally appropriate and safe recruitment method was employed to recruit, facilitate, openly communicate, and engage survivors. The four focus groups with survivors were conducted in four cities across British Columbia. Recruitment involved collaborating with community social services. The resulting transcripts will undergo manual coding and thematic analysis. The development of an intersectional practice framework for improved, well-coordinated, and collaborative service delivery among health-care, police, and community social services has safety and health implications for this population.

Understanding Patient Involvement and Educating Interprofessional Health-Care Teams

Kelly Kilgour, *University of Ottawa*

Angus McMurtry, *University of Ottawa*

Katherine Moreau, *University of Ottawa*

This presentation introduces an active doctoral action research study conducted on two interprofessional teams in a Canadian

hospital. Health organizations are keenly improving interprofessional collaboration (IPC) and patient involvement (PI) with the goal of enhancing patient outcomes. IPC involves health-care workers from different professional backgrounds working together to deliver more safe, effective, and comprehensive services; IPC is an important part of Canadian health-care delivery. Another development is PI in health decisions, empowering patients and taking advantage of their care recipient insights; however, surveys mainly underpin this research. Qualitative research on PI and IPC is therefore essential for quality patient care. Action research provides an active, systematic framework for inquiry while supporting collaboration between researcher and diverse stakeholders (Stringer, 2008). The research objectives are to (a) gain an understanding of PI and perspectives of IPC teams and (b) educate and collaborate with IPC teams to better incorporate PI in their practices. Phase 1 results, from patient interviews, will be summarized followed by collective discussions of future strategies for the researcher to collaborate with and facilitate learning among patient advocate volunteers and IPC teams to improve PI in their team practices (Phase 2). Specifically, patients' perspectives of the IPC teams, their involvements with the teams, the shared decision-making with respect to voicing pertinent health-care decisions, and further educational suggestions will be considered. This study and presentation may assist participants to gain a greater understanding of how to foster improvements in their IPC team practices as well as PI integration and impacts.

“I’m Hating My Life Right Now”: Text Messaging Peer Support Among Counseling Students

Rae A. Kokotailo, *University of Calgary*

Alysha S. Chan Kent, *University of Calgary*

Alexander J. Choy, *University of Calgary*

The journey through graduate school to become a counselor is inherently challenging. Consequently, many students face emotional stress. Peers, through a shared understanding of their experience, offer a unique source of support. This pilot study uses focused ethnography to understand how counseling psychology graduate students engage in emotional support with a peer through the use of text messaging within a naturalistic context. A three-member peer support group, comprising the researchers, served as the convenience sample. In this manner, the researchers both took part in and analyzed the experience of text-messaging-based peer support. Transcripts of emotional peer support interactions were obtained through sampling the participant-observers' naturally occurring emotional text message conversations. Elements of Braun and Clarke's thematic analysis and content analysis were used to categorize the raw data. The main findings indicate peer support bilaterally encompasses action, connection, disclosure, hearing, initiation, shared happiness, and solidarity. Within a support conversation, supporters predominantly used connection statements (which included reassurance, encouragement, validation,

empathy, care/concern, optimism, and normalization), whereas supportees mainly utilized emotional disclosure. These preliminary findings suggest that text messaging offers an immediate, intimate, and readily available platform through which peers can actively create a supportive dialogue.

Implications of Exclusion: Immigrant, Work, and Health Research

Agnieszka Kosny, *Institute for Work & Health*
Stephanie Premji, *McMaster University*

Recent immigrants and refugees are overrepresented in industries and workplaces where there is a higher risk of injury. Many workers new to Canada end up in “survival jobs” because their credentials are not recognized, they have few social networks, lack work experience in the country of arrival, and do not have full proficiency in English or French. Compared to Canadian-born workers, newcomers are more likely to do shift work, work in physically demanding jobs, and not receive training. These conditions are known to expose workers to higher risk of injury and lead to poor health. While regulatory bodies (e.g., Ministries of Labor) regularly identify newcomers as “vulnerable workers,” research in the area of work and health regularly excludes linguistic minorities, recent immigrants, and refugees. Using research examples from labor studies and public health, we examine the implications of exclusion for understanding the circumstances of workers who are disproportionately at risk of injury, the development of sound public policy, and the advancement of social justice. We argue that the exclusion of these participants in qualitative health research infringes upon the principle of fairness and equity in research participation as set out in the Tri-Council ethics guidelines. Building on the critique of feminist scholars who have challenged research that does not consider gender, we highlight what is missed when we exclude linguistic minorities and newcomers from work and health research and what can be gained by resisting these practices. This presentation is linked to the one submitted by Dr. Premji, “Overcoming the Difficulties of Inclusion of Linguistic Minorities in Qualitative Health Research: Lessons from Occupational Health.”

Wisdom to Action: Mobilizing Youths’ Lived-Experience Knowledge to Inform Mental Health Services

Lisa Lachance, *Dalhousie University*
Eugenia Canas, *Western University*
Alicia Raimundo, *Wisdom2Action Network Youth Advisory Council*

Effective mental health care for youth requires research and knowledge mobilization approaches that include diverse forms of knowledge including the knowledge of lived experience. Across Canada, service-improvement initiatives are increasingly engaging young people as advisors and partners in research, with a resulting wealth of evidence that is often qualitative, individual,

and highly contextual to the pluralistic nature of youth as a population. Methods to effectively share new knowledge emerging from the lived experiences of youth remain under studied. How does the wisdom of youths’ lived experience impact the design of mental health services? What can knowledge translation practices do to ensure youth voices are integrated in meaningful ways? Presenters will explore these questions by reflecting on national-level activities of the Wisdom2Action Network (formerly the Children and Youth in Challenging Contexts Network). Since its inception in 2011, this Network has fostered an integrated community of members that includes 78 academics from 34 universities and more than 124 community-based service organizations, policy makers, and community groups. Wisdom2Action has also engaged young people with histories of service use as active participants in all activities including organizational governance. Wisdom2Action initiatives examined in this presentation include the Network’s long-standing Youth Advisory Council as well as its Wisdom-to-Action events. As will be described, the diverse contributions made by qualitative and participatory approaches that engage youth provide both challenges and opportunities in bringing wisdom to action. This practice-based reflection calls for a deeper interconnection between participatory engagement and knowledge mobilization approaches. Emergent best practices will be shared.

Culture and Birth Outcomes in Sub-Saharan Africa: A Literature Review

Rachel Lang-Baldé, *Clemson University*
Roxanne Amerson, *Clemson University*

The sub-Saharan African region experiences 550 maternal deaths daily, equating to approximately 201,000 maternal deaths per year or 546 deaths per 100,000 live births. While other regional rates experienced significant reductions, sub-Saharan African rates of maternal mortality remain staggeringly high; in spite of this, limited research has focused on culture as a factor in maternal deaths. Thus, this review of current literature, using PRISMA guidelines and guided by the theoretical framework of Dr. Leininger, found 25 associations of culture, direct or indirect, to pregnancy and birth outcomes in women of childbearing age. The guiding research question was: What is the current evidence within the last 15 years on cultural beliefs, practices, and traditions that influence birth outcomes for women in sub-Saharan Africa? Three relevant categories emerged from the literature: birth outcomes, maternal care-seeking, and maternal culture care, as well as seven distinct categorizations of culture, offering persuasive evidence of the need to further explore the influence of culture on birth outcomes. To prevent this continued tragedy and to increase the involvement of the women themselves, qualitative health research must focus on understanding how culture impacts maternal health outcomes. By engaging directly with childbearing women and their birth attendants, research can expand its understanding of the various cultural beliefs, practices, and traditions of birth and motherhood. Through listening to women’s voices and engaging with their unique lived

experience, research can help women negotiate biomedical and midwifery models of care, while simultaneously respecting and supporting culturally constructed traditional childbearing preferences.

A Bench Is More Than Just a Bench: Exploring Place-Based Social Inequalities in Smoking Through the Social Meaning of Public Benches

Josée Lapalme, *Université de Montréal*

Nicole M. Glenn, *Université de Montréal*

Katherine L. Frohlich, *Université de Montréal*

Smoking prevalence in Canada has significantly declined but remains high in socially deprived neighbourhoods. To better understand place-based social inequalities in smoking, the Interdisciplinary Study of Inequalities in Smoking has collected quantitative and qualitative data on neighbourhood-level smoking. The qualitative data revealed that participants attributed multiple meanings to public benches and that these shifted by neighbourhood. Inspired by Heidegger's "thing" piece, we asked: What makes the public bench unique and meaningful? What might this reveal about the way social inequalities in smoking are shaped by the objects in our local environments? Public benches are structures made up of a rigid, flat surface and of sturdy, weather-resistant materials. They invite one to sit and stay, but not for too long, as they are not necessarily comfortable, unlike benches that we have in our homes or garden. They are staples of urban architecture, mostly found in parks, at bus stops, and along promenades. Interviews and observations revealed the multiple meanings benches held for residents that went well beyond their intended use. For instance, in high deprivation neighbourhoods with permissive smoking norms, benches represented a landmark and gathering point for community members including smokers. Conversely, in low deprivation places with restrictive anti-smoking norms, benches were places of segregation; smokers used benches removed from where non-smokers gathered. We argue that by reflecting on the "thingness" and multiple place-shifting meanings of the bench, we can see how seemingly ordinary, inanimate public infrastructure can animate local social life and place-based practices such as smoking.

Revitalizing Roles: The Inclusion of Indigenous Elders in Contemporary Judicial Contexts

Karen Lara, *Athabasca University*

The emergent overrepresentation of Indigenous persons incarcerated within the Canadian criminal justice system highlights the ineffectiveness of Western methods of justice in addressing offending behavior. Indigenous justice practices diverge dramatically from retributory measures, reflecting an Indigenous worldview fundamentally based

in the relationship with and connectedness to all things. Elders are integral to these processes, maintaining a vital link of cultural identity, as well as offering support and guidance through the transmission of traditional teachings and experience. The goal of this study is to delve deeply into understanding the current role of elders in contemporary justice practices with Indigenous offenders, in a collaborative and relationship-based manner that honors the sacredness that defines Indigenous research.

Gender Performativity in Nursing: Confronting the Construct of the Ideal Nurse

Barb Le Blanc, *University of Ottawa*

Dave Holmes, *University of Ottawa*

Amelie Perron, *University of Ottawa*

There are factors that affect the nursing profession's ability to recruit, retain, and successfully graduate male nurses including lack of acknowledgment of the diverse needs of men, particularly in the education system. The existing literature shows that there are often limited opportunities for mentorship, perceived sexism on the part of some educators, and pressure to conform, with little recognition for the differences between men and women and how they learn and communicate. The male nursing student is often exposed to only a feminine-gendered construct of the nurse, incorporating stereotypical behaviors and responses equated with the (feminine) nursing ideal. This interpretative phenomenological study, utilizing the work of van Manen, examines the lived experience of the male nursing student. Theoretical underpinnings include queer theory and critical concepts including Butler's performativity and Foucault's disciplinary power. Male students have a sense of isolation and disengagement from their peers and the faculty. It has also been identified that the nursing education and socialization process is focused on the female perspective and the feminine mantra, which serves to perpetuate the construct of the ideal nurse. The need to meet the gender performativity expectations within this female-dominated profession creates a learning environment that puts little emphasis or importance on meeting the needs of minorities within the profession. The study has generated key strategies to enhance the success of all students.

Beyond Double Blind Research: On Subjectivity and Being a Woman in Research With Men

Maya Lefkovich, *University of British Columbia*

A researcher is many things. The intersection of professional and personal identities informs how a qualitative researcher may conceptualize knowledge production and subsequently conceive of and design a study. Despite this, there is a lingering discourse in research whereby objectivity is the gold standard of research, and a professional distance between the researcher and the researched should be achieved. Within this understanding, positionality or

subjectivities is often read as bias and relegated to a limitation section of a paper to be disclosed. In my experience as a cis female qualitative researcher studying men's health and masculinities, I am commonly asked about the bias I impose in studies, and how my gender and presumed subjectivities limit my interactions with male participants, my ability to access "men's spaces," and the quality of data I collect and interpret. Within the context of women studying men (and the common critiques I have faced), this presentation will reflect on gender in relation to research spaces, qualitative interview dynamics, and writing/representation. I will grapple with the following questions: (1) how are asymmetrical positionalities between researchers and participants illustrative of broader gender power dynamics and (2) in what ways can these asymmetries contribute to useful strategies (rather than or in addition to limitations) in qualitative health research?

Interviewing Parents of Babies Born With Congenital Anomalies: Insights for Phenomenological Researchers

Gillian Lerner Meyer, *University of Alberta*

The interview is a common method employed in qualitative health research. For phenomenological studies, the interview is focused on gathering experiential accounts of a lived experience. Even though phenomenological analysis rests on the condition of having access to this material, it is not always recognized how difficult it can be to obtain concrete, experiential accounts of phenomena. The research interview in health care is also an ethically sensitive part of the research process, and participants may become distressed or upset when talking about intimate aspects of their experiences. Using examples from a research project exploring the experience of parents whose child was born with a congenital anomaly in the neonatal intensive care unit, this presentation will invite the researcher to consider the phenomenological interview. The hope is to offer some methodological and practical insights including suggestions for preparing for the interview, types of questions to consider, the tone of the interview, and some ethical considerations. The strongest recommendation regards the manner of the interviewer, whose approach must include a phenomenological attitude of wonder and openness, the central method of phenomenology.

Methodologic Considerations for Design Research: An Example of Qualitative Design Research for "Good" NICU Antenatal Consultation

Gillian Lerner Meyer, *University of Alberta*
Michael van Manen, *University of Alberta*

The activity of design concerns itself with "that which could be." As such, the design researcher is oriented not simply to describe or analyze a particular situation but instead to explore possible futures that the artefacts of design create for a particular problem. We describe the use of a design framework to

research how to support antenatal consultation with families when the possibility of premature delivery and admission to a newborn intensive care unit exists. Empirical qualitative methods employed in this project included focus groups, interviews, and observations. The outcome of this study is not only a more holistic understanding of what constitutes a "good" antenatal consultation but also the product of design research in itself: design artifacts for expectant families and health-care professionals to support antenatal consultations. This project therefore ultimately provides an example of how qualitative health researchers may meaningfully engage with families and health-care professionals to directly contribute to actual health-care practice.

Using Participatory Visual Methods to Understand Youth Resilience

Linda Liebenberg, *Dalhousie University*

Despite the increased effort to understand resilience processes in the lives of youth facing higher than normal risks, definitions and theories remain largely homogenous and reflective of westernized cultures. Consequently, our understanding of resilience needs to be challenged, allowing for a more diverse understanding resilience processes and required resources. In this way, our understanding of resilience can become more relevant to children and youth around the globe. However, many of the resilience processes youth engage with to do well despite the adversity that they are facing are obscured to them. This is because these processes may be taken-for-granted everyday aspects of their lives or aspects that remain outside of their literal line of sight. This raises questions about the ways in which we research young lives. Additionally, a core goal of resilience research is to facilitate positive change in the lives of marginalized youth and the environments through which they move. This goal raises questions regarding the impact (or lack thereof) of our research findings and the ways in which we increase knowledge uptake. This presentation will review the use of participatory visual approaches in research with youth and the ways in which this facilitates exploration of the taken-for-granted and youth engagement as knowledge mobilizers of research findings. Specifically, it will outline the ways in which participatory action research aligns with the challenges of resilience research, situating participatory visual methods within these two theoretical frameworks. The presentation will conclude with a research exemplar.

Meaningful Engagement of Youth in PAR: The Role of Community Partnerships

Linda Liebenberg, *Dalhousie University*
Arnold Sylliboy, *Eskasoni Mental Health Services*
Doreen Davis-Ward, *NunatuKavut*
Amber Vincent, *Nunatsiavut Government*

This presentation will review the process used in a PAR project with Canadian Indigenous youth aimed at understanding their civic and cultural engagement as a component of mental health promotion. Specifically, we reflect on the approach taken together with the core role of community partners in facilitating

youth participation in this project. The process we used had three key aspects which facilitated effective youth engagement. First was flexibility and adaptability of the original study design, allowing the young people to adjust the project design, increasing their comfort levels and in doing so, assume as much or as little ownership of the process as they wanted. Second was building on preexisting relationships between mental health service provider staff and the community, which accelerated the establishment of trust. Through this trust, new relationships within the research team were able to develop. Third was the support of the youth engagement by the service provider staff, which provided support as required. This process improved the quality of the data collected, related findings, and for effective dissemination. Importantly, this staff–youth interaction has also increased longevity of the dissemination process. Our intent in reflecting on this process is to further the dialogue on how to meaningfully engage ordinarily silenced and/or marginalized youth in research and evaluation as well as the sharing of findings.

Pitfalls and Benefits of Public Engagement in Health Equity Research: A Digital Storytelling Project With Persons Who Have Low Literacy

Christine Loignon, *Université Laval*

Sophie Dupéré, *Université Laval*

Karoline Truchon, *Université de Sherbrooke*

Lynda Benhadj, *Université de Sherbrooke*

Persons living in poverty or with low literacy are too many often studied as “objects of research.” In this regard, participatory approach and visual methods are promising to encourage their participation in health research. We started a patient engagement project in 2015 to involve persons with low literacy in applied research to reduce and solve health-care inequalities. The aim of this presentation is to discuss the ethical and methodological challenges of conducting research with persons with low literacy. We will present our methodological processes to establish confidence and sustain an authentic participation. The main objective of our project was to identify barriers and facilitators of active participation of persons with low literacy in research. This study relies on a partnership developed with three community organizations located in Montreal and Quebec from 2015 to 2017. We used participatory methods to support the involvement of persons with low literacy. As nonacademic researchers, they participated to the identification of the research objectives and choose to develop a digital storytelling (DST) project. They were involved in the co-creation with researchers, a visual anthropologist and a video editor, of reflexive autobiographical videos. We will discuss the pitfalls of the processes and outcomes of DST, especially the empowerment process for persons with low literacy. We will also share our concerns surrounding the ethic consent and the conditions to avoid a tokenistic involvement into the production of videos and the dissemination. This study reflects on a unique patients’ engagement project involving persons with low health literacy that contribute to the “science of engagement.”

Exploring Interpersonal Processes in Personalized Obesity Management Consultations in Primary Care and Impacts on Patients’ Everyday Life

Thea Luig, *University of Alberta*

Robin Anderson, *Edmonton Southside Primary Care Network*

Denise L. Campbell-Scherer, *Alberta Diabetes Institute, University of Alberta*

People with obesity currently do not receive sufficient primary care services that address the complexity of root causes, drivers, and barriers to management. To develop an effective approach that can be tailored to patients’ contexts, it is essential to understand how people experience the consultation including interpersonal work, communication, and content, and how this impacts their ability to make changes to improve health. This research collaboration with a primary care organization and patient champions aims to pilot and refine a personalized approach to obesity assessment and care planning that uses the 5As of obesity management and collaborative deliberation with the goal to generate evidence for a randomized control trial. To do that, we video-recorded consultations with 20 people with obesity, followed by loosely structured interviews with patients and clinicians. To understand everyday life impacts, patients journaled about experiences, decisions, emotions, and outcomes and returned for two follow-up interviews at 3 and 6 weeks.

Using a dialogical narrative approach, this presentation explores patients’ stories of their weight as anchor for three processes: (1) co-construction of personal causes, barriers, and current challenges; (2) collaborative deliberation about patients’ preferences, care options, and priorities; and (3) shifting patients’ narrative of their weight, health, and self by validating their experience and efforts, emphasizing strengths, and identifying realistic strategies that make sense in their life context. These interpersonal processes proved key for enhancing patients’ confidence and capacity in making everyday changes to improve health and for optimizing interdisciplinary care to address root causes and barriers.

“People Can Tell Me Things, But If I Don’t Take Action It Doesn’t Work”: The Meaning of Engagement to Service Users at the Prevention and Early Intervention Program for Psychosis (PEPP-Montreal)

Kevin MacDonald, *Douglas Mental Health University Institute*

Tovah Cowan, *Douglas Mental Health University Institute*

Manuela Ferrari, *Douglas Mental Health University Institute*

Srividya Iyer, *McGill University*

In mental health treatment research, service engagement is often seen as a facilitator of remission and recovery.

Quantitative studies usually operationalize engagement in treatment according to the medical model, prioritizing attendance and medication adherence, and occasionally acknowledging the therapeutic alliance as an influence on service engagement. This study sought to explore the perspectives of youth who were or are service users at Prevention and Early Intervention Program for Psychosis-Montreal, an early intervention program providing care for youth experiencing psychosis, on their engagement in treatment. Semistructured interviews were conducted on topics including their experiences and perceptions of treatment, and how they defined their engagement. Five individuals who had discontinued services and 19 individuals engaged in services to varying degrees took part in this study. Inductive thematic analysis was used to analyze data, and then relationships between themes were identified to create the proposed framework to capture service users' meaning of engagement. Some service users' definitions of engagement were in line with the medical model (e.g., attendance, medication adherence, and complying with the treatment team), while others conceptualized engagement as oriented toward subjectively defined recovery (e.g., engagement is your choice, only you can implement changes, and focusing on self-care and life improvement). These positions on engagement were sometimes held simultaneously, with emphasis on service users' choices about their treatment. Other participants described engagement in life and engagement in treatment as incompatible. This study suggests that researchers and clinicians may be disconnected from some service users' understanding of engagement in services and proposes a new framework grounded in service users' experience.

Engaging Multiple Stakeholders in Qualitative Research Design Through e-Methods

Allison MacNeil, *Douglas Hospital Research Institute*
Srividya Iyer, *McGill University*
Ashok Malla, *McGill University*

Patients, families, clinicians, and decision makers are increasingly regarded as partners in health research. Engaging them, though, often proves challenging. There is a need for engaging, resource-efficient ways to build their capacity and seek their inputs on research questions and methods. This presentation provides an overview of how these challenges were addressed by ACCESS Open Minds, a pan-Canadian youth mental health research network. ACCESS used e-methods to gather the inputs of multiple stakeholder groups in crafting its qualitative research strategy. We created an online survey asking stakeholders to submit research questions that were priorities for them and to propose suitable qualitative methods. An engaging infographic, explaining the fundamentals of qualitative research, accompanied the survey. The survey was responded to by

33 stakeholders from 10 sites across Canada, of which four were Indigenous. Of these stakeholders, eight were youths or carers, 11 were service managers, and 14 were researchers/clinician-researchers. Responses were analyzed thematically by a research assistant and a member of ACCESS's youth council. "Engagement," "pathways to care," "quality of care," "service transformation," and "values/culture" emerged as the main priorities to be targeted by ACCESS's qualitative research. Respondents desired the tapping of diverse perspectives in our qualitative research through the inclusion as informants of youths, their carers, clinicians, and service providers. The top methods proposed were interviews, focus groups, and sharing circles. Using an online survey and an infographic allowed broader, more effective stakeholder engagement. This approach has implications for other initiatives that seek to engage diverse stakeholders in shaping research priorities.

Policy Evaluation of a Potential Observation Unit (OU) for Acute Decompensated Heart Failure (ADHF) Patients

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Cheng Zhu, *McGill University*
Beste Kucukyazici, *McGill University*

Heart failure (HF) has been one of the growing epidemics in North America. With over one million HF patients hospitalized each year, HF is the single leading factor of hospitalization in the United States. Given the ongoing trend, by 2030, over 10,000 more Canadians are projected to live with HF compared with 2013. HF has also exposed a heavy economic burden on health-care system. Heart and Stroke Foundation estimated the direct costs of treating HF to be US\$34 billion per year, most of which due to expensive hospitalizations. Acute decompensated heart failure (ADHF), defined as "the sudden or gradual onset of the signs or symptoms of heart failure requiring unplanned office visits, emergency room visits, or hospitalization," is among one of the major factors of ED visits. Although only ADHF patients with worsening clinical conditions are recommended to hospitalization, currently most patients are admitted due to higher risk of early postdischarge events including morbidity, mortality, and readmission. ED physicians tend to significantly overestimate the severe complication incident due to early discharge, resulting in unnecessary and costly systematic hospitalization. In this study, we design a decision support tool to evaluate clinical and economical advantages of a dedicated observation unit (OU) for ADHF patients. In this OU, low-and intermediate-risk ADHF patients are identified, treated, and discharged home without being exposed to early postdischarge events, whereas the high-risk HF patients are hospitalized. The decision support tool evaluates nine potential policies: admission, capacity, and discharge policies for the potential OU.

The Benefits and Limitations of Interprofessional Education Teamwork: Occupational Therapy Students' Perspectives

S. Maggie Maloney, *University of Toledo*

Research indicates collaborative and interdisciplinary care optimizes health outcomes for clients (World Health Organization [WHO], 2010). WHO calls for health-care educators to develop curricula that guide students to become “collaborative practice-ready” health-care professionals in order to work effectively within an interprofessional team prior to graduation. Interprofessional education (IPE) programming affords students this opportunity to learn about, from, and with other disciplines. As part of an IPE course that included students from 10+ disciplines, occupational therapy (OT) students wrote two reflective journal assignments which were submitted electronically. Ethics Board approval was secured to conduct a retrospective analysis of the journals, and 22 of the 40 journals from the OT students were de-identified and randomly selected for analysis. Charmaz’s (2006) qualitative research methodology was followed. The PI (an experienced qualitative researcher and faculty member) trained two OT students (not members of the examined cohort) on the analysis process. All three researchers individually intensively read and analyzed each journal at an incident level to ascertain the participants’ meaning of their interactions within the IPE team and with clients and agency officials. The researchers also met 3 times to discuss the findings and collectively determine the themes. Six key themes emerged: Effective communication makes a team work, collaboration is necessary, each discipline is unique, there is power in holistic team coverage, client-centered care is essential, and personal transformation occurs during uncomfortable situations. The findings support the value IPE experiences have to assist OT students to optimize their knowledge and skills and understand those of their professional colleagues, prior to entering the work force

“It’s Always Crunch Time”: A Phenomenological Study of Single-Mother University Students’ Lifestyle Imbalance and Stress

S. Maggie Maloney, *University of Toledo*

This study examined the lived experiences of single-mother university students in order to understand their perspective on performing daily occupations within their multiple roles of mother, student, employee, friend, and/or daughter. Their physical, emotional, social, and cognitive well-being was explored in relation to the five dimensions of Matuska and Christiansen’s model of lifestyle balance. Institutional review board approval was secured, and nine single-mother volunteers from a large, urban, American university were recruited.

They ranged in age from 20 to 38 years; five were undergraduate students, five were African American, and their children had a mean age of 7.1 years. Individual interviews lasted between 1 and 3 hr and were transcribed verbatim. Two analysts individually read and reread the transcripts multiple times (guided by Giorgi, 2009) and then met 3 times to intensively discuss the findings. The mothers indicated they experienced high levels of stress on a daily basis and struggled to maintain personal health and well-being. However, an overarching theme indicated they all embraced this temporary self-sacrifice in order to achieve the unspoken promise of a better life once their higher education is completed. Other emergent themes included role conflict, value of a support system, failures, constant fatigue and stress, and lack of leisure and personal time. This study adds to the growing body of literature within occupational therapy and occupational science to document and explore the negative implications of lifestyle imbalance. Despite the smaller number of participants, the findings deepen health care and higher education professionals’ understandings of the unique needs of this population as they pursue an advanced degree.

The Impact of Concomitant Animal Maltreatment on Adult and Child Survivors of Intimate Partner Violence: Implications for Safety Planning and Intervention

Shelby Elaine McDonald, *Virginia Commonwealth University*
Beth Collins, *Colorado Office of Children Youth and Families*
Anna M. Cody, *Virginia Commonwealth University*
Nicole Nicotera, *University of Denver*

Intimate partner violence (IPV) is a pervasive global health issue. One well-documented tactic of coercive emotional and psychological abuse against intimate partners is cruelty and violence toward household pets. Despite empirical evidence of the strong attachments that IPV survivors and their children experience with family pets, few qualitative studies have rigorously explored how women with children experience and respond to maltreatment of companion animals in the context of relationships characterized by IPV. The current study advances the nascent qualitative research on the intersection of IPV and animal cruelty by exploring the following questions in an ethnically diverse sample of pet-owning IPV survivors with children: (1) How do women with children experience threats to and harm of companion animals in households where IPV occurs? and (2) In what ways does concern for companion animals impact their decisions to stay with or leave an abusive intimate partner? One hundred and three women (46% ethnic minority) were recruited from community-based domestic violence shelters in a Western U.S. state as part of a larger mixed-methods phenomenological study. Qualitative interview data were analyzed thematically in Atlas.ti using the process of template analysis. Five themes emerged: (1) animal maltreatment by partner as a tactic of coercive power and control, (2) animal maltreatment by partner as discipline or punishment

of pet, (3) animal maltreatment by children, (4) emotional and psychological impact of animal maltreatment exposure, and (5) pets as an obstacle to effective safety planning. Implications for safety planning, prevention, and intervention are discussed.

Bicultural Practitioners in Mental Health Settings: A Constructivist Grounded Theory Study

Susan McDonough, *Latrobe University*

Rates of mental health service use among mainly non-English-speaking immigrant and refugee Australian communities are much lower than those recorded for Australian-born individuals. This reflects differing family, community, and service understandings of mental health, recovery, and help seeking as well as the structural effects of social, cultural, and economic inequality. In recent years, improving the capability of all practitioners and services to respond to culturally and linguistically diverse populations has been the focus of multicultural mental health policy and practice. Less attention has been given to ensuring community diversity is reflected in the diversity of the mental health workforce itself. This study explores the work of practitioners who assist people experiencing mental health issues or emotional issues with whom they share a similar cultural, linguistic, or faith background. Using a mixed, sequential data collection methodology to explore their roles, tasks, and experiences, I gathered largely quantitative data from 44 participants in an online survey before conducting 19 semistructured interviews. A constant comparative method consistent with constructivist grounded theory was used to conceptually analyze emergent patterns. Three main categories of practice emerged. From their perspective, these practitioners are “working to adjust” circumstances and conditions for service users, “being with” services users in ways that evoke home and family, and “acting in solidarity” with service users as they negotiate care. These findings have implications for understanding how bicultural practitioners enhance the provision of culturally responsive and safe of mental health services.

Bridging the Experience to the Journey: A Discussion of Longitudinal Designs in Qualitative Investigations About Mental Health

Sarah McIlwaine, *Douglas Mental Health University Institute*
Manuela Ferrari, *Douglas Mental Health University Institute*
Srividya Iyer, *McGill University*
Jai Shah, *McGill University*

Mental health treatment: A pendulum between wellness and illness marked by cascades of symptoms and diagnoses as one journeys toward recovery. Despite its longitudinal nature, qualitative research investigating mental illness and recovery often uses a single encounter to capture a fluid experience that may have been endured for weeks, months, or even years. On the

occasion that the fluidity of mental health is explored, it is within the constraints of the 3-, 6-, or 12-month time line that is typically seen in quantitative approaches. This presentation will discuss standard qualitative methods used in mental health research and problematizes the lack of longitudinal qualitative approaches regarding the experience of early psychosis and its associated at-risk state. For example, although phenomenological methods can produce a rich account of the continuity of experience in relation to social and cultural contexts, researchers can get lost in this approach’s extensive ideological discourse. To incorporate phenomenological practice in a more accessible way, we are proposing a novel longitudinal design to investigate the subjective experience of need in young people who may be vulnerable to developing psychosis currently attending the Clinic for the Assessment of Youth at Risk in Montreal. Specifically, we will interview these youths for 4 months, enabling us to capture their experience of need during the first months of receiving services. This design will not only explore the subjective experience of the at-risk mental state but will highlight how the ever-changing contexts that young people navigate can shape their service needs.

Educating and Preparing Future Occupational Therapists in a Digital World

Carol McKinstry, *La Trobe University*
Amanda Kenny, *La Trobe University*
Teresa Iacono, *La Trobe University*

Higher education is moving away from didactic teacher focused pedagogies and implementing strategies such as blended learning and flipped classrooms to transform learning environments. The focus is on student engagement with information communication technologies, but this fails to develop digital literacy capabilities needed for health environments of complex digital and technological change. This study aimed to develop a digital literacy framework and mapping tool to guide curriculum design. Within an action research methodology, cooperative inquiry and a knowledge to action framework were used. Semistructured interviews with telehealth experts were conducted, with Belshaws eight elements of a digitally literate individual used to guide analysis. This process led to a contextualized digital literacy thematic framework that reflected the capabilities required of health graduates. Overall and level descriptors for basic, medium, and advanced capabilities were developed. The framework was used to develop a curriculum mapping tool to identify digital literacy capabilities. The developed framework comprised six themes: creating understandings, developing the culture, using the full capacity, building connections, owning the space, and transformative thinking. The validity of the framework was tested by applying the mapping tool to a graduate entry occupational therapy curriculum. The centrality of digital literacies is beyond proficiency with information communication technologies. Digital literacies must be interwoven within undergraduate curricula rather than included as

a specific subject or module. The developed materials can support and help embed multiple learning and teaching opportunities, building fundamental capabilities of digital literacy required for contemporary and future health care.

Behavioral Consultation to Schools via Telehealth: The Medium Is Not the Message

John D. McLennan, *Children's Hospital of Eastern Ontario*

A pilot consultation service to support the implementation of behavior modification-based strategies to help students struggling with attentional and behavioral difficulties was provided via telehealth to teachers in elementary schools. A qualitative evaluation of this pilot service used a case study approach to explore the viability of providing this type of consultations to schools via telehealth. Data sources included interviews (recorded and transcribed) with participating parents and school-linked personnel and participant observations by the consulting psychiatrist, chart reviews, and school information. Immersion and crystallization were the principal analytic approaches employed within this case study. A total of 33 consultations were provided by a child psychiatrist to six different schools over 1 year. The telehealth link using tablets, existing computer hardware, and new software was viewed as the innovative aspect of the project. Whereas modest challenges were experienced in employing these technical components, the content of the consultation, and explicitly behaviorally based, appeared to elicit greater challenges. The ambivalence of school-linked personnel about the content appeared to contribute to the service's mixed uptake and implementation. Concepts that appeared to underpin the ambivalence included (i) concerns the intervention relied on "external" versus "internal" student motivators, (ii) beliefs that such interventions are already routinely in place, (iii) notions that data-driven outcome monitoring is not essential, (iv) resistance to intervention formalization, and (v) competing time demands. In the enthusiasm for expanding health services via telehealth, there may be an inadequate consideration of receptivity to core service content. The medium, in this case, was not the message.

Transforming and Decolonizing the Relationship Between Non-Indigenous Counselors and Indigenous Communities: How Allies Can Be Helpful in Mental Health Service Provision

Kyla McPhee, *University of Calgary*

Due to 500 years of colonial violence, cultural oppression, forced assimilation, and intergenerational trauma, there are continued psychological, emotional, spiritual, and mental consequences within Canadian Indigenous communities. Despite overwhelming evidence that Western approaches to counseling are often culturally inappropriate for Aboriginal clients, many

counselors continue to work from a Western framework that does not take into account the importance of Indigenous cultural beliefs and Aboriginal approaches to mental health, contributing to further cultural oppression and colonization. A shortage of counselors of Aboriginal descent, as well as high turnover rates among non-Indigenous counselors, results in limited access and disruptions in care. Reconciliation necessitates a transformation of the current relationship between non-Indigenous counselors and Indigenous communities. Therefore, it is imperative to investigate the following question: How have members of the Indigenous community experienced allies being helpful in mental health service provision? In this pilot study, I interviewed two self-identified Aboriginal individuals who work within the mental health system. I analyzed interview data using a descriptive phenomenological methodology to depict Aboriginal individuals' experiences of allies being helpful within mental health service provision. The findings offer insights into (a) How non-Indigenous and allied mental health service providers can work with Indigenous populations in a culturally sensitive and responsive manner and (b) potential issues regarding how allies work with Aboriginal clients and what might be done to rectify these problems.

Experience Mapping the Transition From Child to Adult Mental Health Services: Perspectives of Youth, Family Members, and Service Providers

Ashleigh Miatello, *McMaster University*

Gillian Mulvale, *McMaster University*

Christina Roussakis, *McMaster University*

Discontinuities between child and adult mental health systems place youth with mental disorders at high risk once they turn 18 and face a system that differs with respect to eligibility criteria, philosophical approach, mix of providers, and family involvement; and where service shortages often mean delays in access. In order to design effective service improvements, it is essential to understand transition experiences of youth, family members, and services providers. In this presentation, we will present "experience maps" developed during research to improve youth to adult mental health service transitions in Hamilton, Ontario. We analyzed interview data from youth across Ontario aged 16–24 years receiving mental health services ($n = 16$), their family members ($n = 9$), and services providers ($n = 10$) gathered between August 2014 and December 2015. We used interpretive phenomenological analysis to identify "touch points" in their care journeys where experiences were highly emotionally charged (positively or negatively). We then held separate focus groups with youth ($n = 8$), family ($n = 10$), and service providers ($n = 15$) from Hamilton to refine, validate, and prioritize the touch points and to collectively create an "experience map" for each perspective. Following the focus groups, the research team identified 17 common touch points to develop a combined transition experience map from the three perspectives. This approach offers a tangible way to harness the

experiences of service users, families, and service providers to identify priorities for health systems improvement, while promoting mutual understanding. It can serve as the basis for codesigning improvements and is applicable to other ages and health conditions.

More Personalized Care: Pediatric Vaccine Hesitancy and the Patient–Provider Relationship

Hana Mijovic, *Vaccine Evaluation Center*
Devon Greyson, *Vaccine Evaluation Center*
Eve Dubé, *Institut National de Santé Publique du Québec*

Parents and health-care providers (HCPs) sometimes hold divergent views on pediatric vaccinations. We conducted semistructured interviews with 4 immunizing HCPs and 10 parents in British Columbia, Canada, in order to characterize interactions around vaccinations and understand why parents' decision to vaccinate may change over time. Parents were purposively selected to represent maximum diversity across the vaccine hesitancy spectrum. Data were analyzed using qualitative thematic analysis influenced by constructivist grounded theory. Inductive coding of interview transcripts was done by the first author with the assistance of NVivo software. This led to an iterative process of theme development and theory generation by the entire research team. HCPs felt that interactions around pediatric vaccinations often provided an opportunity to develop trusting relationships with parents. However, accommodating vaccine hesitant parents was challenging within the structured, protocol-driven medical system that does not encourage individualized care. Many parents valued long-term relationships with HCWs and sought “more personal” care. Their decision to vaccinate was influenced by their relationship with HCP and trust in allopathic medicine and also by their interpretation of vaccine information obtained outside the HCPs' office and the views held in their social circles. Our findings indicate that developing such personal and trusting relationships between HCPs and hesitant parents require a tailored approach that acknowledges parents as active and critical information seekers whose decision to vaccinate is based not only on personal beliefs but also on their broader social realities. However, this individualized approach to vaccine hesitancy is challenging to implement within the existing system.

Critical Realist Case Study: An Innovative Research Approach

Kaye Milligan, *Ara Institute of Canterbury*
Jean Gilmour, *Massey University*
Annette Huntington, *Massey University*

This presentation explores critical realist case study (CRCS) as an innovative methodological approach for qualitative research. The ways in which this research approach can

involve and engage participants and citizens within a specific aged care setting is considered and the contribution of those who do participate is acknowledged. The synergies between critical realism and case study will be discussed. The underpinning philosophical origins of critical realism will be described along with the approach critical realists have of reality. The application of CRCS will be explored through the presentation of one qualitative research project in which the clinical decisions that registered nurses make in the residential aged care sector in New Zealand are explained. These clinical decisions impact directly on the experiences and outcomes of frail residents living in rest homes and hospitals. Critical realism is relatively new to nursing research. In this doctoral project, the CRCS approach was found to be highly effective in focusing attention on the social structures that influenced registered nurses' clinical decisions. Several conclusions were reached. The research was successful in providing explanations of the clinical decisions made by registered nurses in the residential aged care setting, as the interrelationships of a range of influential factors were identified. This research approach has provided new insights into the factors which impact the clinical decisions by registered nurses in this particular environment. It has also provided findings that illustrate the complexity of this work environment for the registered nurse. These findings are inspirational for others, considering caring for elders in this context. The methodology has been successful in providing a detailed explanation of multiple mechanisms and has engaged participants in meaningful involvement in research.

The Clandestine Nature of Transcribing: Uncertainties for the Qualitative Researcher

Kaye Milligan, *Ara Institute of Canterbury*
Jean Gilmour, *Massey University*
Annette Huntington, *Massey University*

The purpose of this presentation is to highlight an unexpected challenge I encountered when completing a qualitative research project and to signal what I would have done “had I only known.” The methods utilized in this research project included gathering data via interviews with participants, which proved to be an enjoyable though testing communication process. Once these data were gathered, the audiotaped words were transcribed by professional transcribers into written format. It was at this stage of the data collection and data analysis process that I confronted the unexpected challenge. Should the transcription be “verbatim” or “intelligent verbatim” or “edited transcription”? How should different interpretations of the spoken words be managed? The transcriber heard words and wrote them as written text, and the researcher listening to the same words heard different words that generated different written text. Also, how accurate can the transcriptions be? How accurate should the transcriptions be? Balancing ethical considerations provided a route forward for decisions about which words to accept as data. Key learning,

“had I only known” earlier, would have altered aspects of undertaking the interviews as well as prior clarification of the transcription process.

Relevance of Qualitative Research in Understanding Health Factors

Sukanya Mohanty, *Jawaharlal Nehru University*

The research study on health factors responsible for employment shifts of women construction and domestic workers in slums of Cuttack city in Odisha state of India affirms that the qualitative health research is “the approach” to know “the cause of causes.” The research design was based on mixed methods of survey and case studies so as to develop the findings of quantitative methods with qualitative methods. The survey sample was randomly selected from 12 slums with a sample of 498, and 33 case studies were purposively chosen of this 498 based on the factors cited. Health was cited by at least 20% of the respondents for work-related changes. The study found that health factors identified as the primary factors of work-related changes in the survey coexisted with other factors in women’s lives as women narrated their experiences during interviews. Women’s lives and health was a continuous and interactive process, where in past, present, and future were in a web; the interrelationship of variables established by survey was incomplete without this complexity unraveled by case studies. Further, the article speaks of different stages of research and how different approaches in qualitative research could be used to understand the phenomenon; in this case, employment changes and health factors. The research used grounded theory, particularly, Strauss and Corbin’s approach while collecting the data and Charmaz’s constructive approach while analyzing the data. These two different approaches of grounded theory complemented each other in constructing the context of work changes based on selective areas of inquiry.

Moral Experiences of Crisis Management in a Child Mental Health Setting: Engaging Children, Parents, and Staff Members Through a Participatory Research Study

Marjorie Montreuil, *McGill University*

Restraints and seclusion are routinely used in child mental health settings for conflict and crisis management but raise significant ethical concerns. Contrary to the literature on adult mental health, the perspectives of children on these control measures are almost absent. This study explored the institutional norms, structures, practices, and corresponding moral experiences of children, parents, and staff members around conflict and crisis management in a child mental health setting, with the aim to address certain ethical concerns. A 5-month participatory hermeneutic ethnography was conducted in a child mental health setting offering care to children aged

6–12 years old in an urban context in Canada. Through a participatory research approach, children, parents, and staff members were involved in the research process to contribute to decisions related to research questions, data collection strategies, data interpretation, and dissemination. The results show how the strict structure in place both contributed to and prevented crisis situations. Children perceived control measures as helpful in exceptional cases when there was an imminent risk to someone’s safety and largely disagreed with their use as a consequence for bad behavior. This perspective contrasted with most of the staff who considered control measures contributed to help children feel safe, learn the limits in the setting, and form a trusting relationship. Seeking a rapprochement with children, by getting to know what is meaningful to them and try to bridge these horizons, could help build more authentic trusting relationships that might be more conducive to the implementation of collaborative approaches.

Developing a Gestational Diabetes Risk Reduction and Reproductive Health Education Program for American Indian/Alaska Native Adolescent Females: Perspectives From Key Stakeholders

Kelly R. Moore, *University of Colorado Anschutz Medical Campus*
Sarah A. Stotz, *University of Colorado Anschutz Medical Campus*
Martha Ann Terry, *University of Pittsburgh*

The purpose of this research was to understand key stakeholders’ perspectives on culturally tailoring a validated, pre-conception counseling education intervention originally made for Caucasian and African-American adolescent girls with diabetes. The curriculum will be designed to meet the unique needs of American Indian/Alaska Native (AIAN) adolescent females at high risk of gestational diabetes mellitus (GDM). This curriculum will teach skills for positive mother/daughter communication, increase knowledge about reproductive health and pregnancy planning, and address modifiable risk factors for GDM prevention (i.e., weight management through culturally appropriate healthy eating and physical activity). We employed a constructivist single case study approach, with the developing curriculum, entitled Stopping GDM, as the case. We conducted focus groups and individual interviews with key stakeholders including elected intertribal leaders and tribal health administrators ($n = 12$), AIAN adult women with history of GDM ($n = 5$), adolescent AIAN girls (age 12–20; $n = 13$), AIAN adult female caregivers ($n = 9$), and health-care professionals/experts in AIAN health (seven were AIAN), diabetes, reproductive health, gestational diabetes, and mother/daughter communication ($n = 16$). All participants agreed GDM risk reduction in AIAN adolescents is important, but resources available to AIAN adolescents at risk of GDM are sparse. They recommended the program be native-family and community focused, use “real” stories, include cultural aspects of healthy lifestyle (i.e., traditional foods), and provide tools and resources to address multilevel

barriers to healthy eating, physical activity, and healthy reproductive practices. Empowering girls to make healthy and safe choices by using their community and extended family support systems was prioritized.

Engaging Older Adults in Research on Hospitalization: Acknowledging Their Voices

Jeannine T. Moreau, *University of Sydney*

This ethnographic study involved and engaged seven older adult patient participants. Research methods of participant observations, conversations, and interviews provided a “way in” to hear and see up close their life worlds in an acute care hospital. They were hospitalized for repair of a fractured hip due to a fall. At the time of their admission, they were medically stable and independent. As I followed each participant throughout their length of stay, I listened and observed what they were doing and how they talked about and made meaning of being in hospital. I examined how they characterized their understanding of what was going on. Their confusion, questions, and uncertainties of “what would happen next,” and wondering if they “would ever be the same again” revealed the liminality of their hospital time. They depicted their experience of hospitalization as ambiguous, anxiety provoking, and foreboding. They anguished about what it means to grow old, to potentially lose independence with a deepening awareness of their vulnerability and fragility. Their worries and concerns pointed to a growing sense of what it means to be old signalling a rite of passage, an initiation into elderliness. I argue that in our highly biomedicalized health-care system where patients are objects of care, if care providers are to genuinely provide person-centered care then older adult’s voices, as captured in this study, must be heard, acknowledged, and attended to. The knowledge gained here can offer new understanding to inform care provider knowledge, education, practice, and health policy.

Engaging Youth, Family Members, and Service Providers: Codesigned Prototypes for Improving Youth Mental Health Service Transitions in Ontario

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Experience-based codesign (EBCD) seeks to engage the public in health systems redesign while empowering youth, family members, and service providers. It identifies “touch points” that are powerful experiences in the health-care journeys of each participant type who subsequently work together to codesign improvements to enhance experiences. We held a codesign event in March 2017 to improve youth to adult mental health service transitions in Hamilton, Ontario. Four touch points were identified as co-design targets based on input from

the research team, a project steering committee, and three focus groups. In the first codesign round, separate groups of youth ($n = 4$), family members ($n = 6$), and service providers ($n = 6$) tackled a compelling touch point for each perspective. This involved (i) honing in on WHY each problem exists, (ii) individually brainstorming potential solutions, (iii) collectively combining and prioritizing solutions, and (iv) developing initial prototypes. The other two participant groups then enhanced these initial prototypes in turn. In the second co-design round, three parallel mixed groups worked to prototype solutions for a fourth touch point that was common across participant perspectives. The entire group commented and enhanced prototypes during plenary discussions. Prototypes included an online portal, overlapping age criteria and funding, a family navigator role, a central intake process, a transitions protocol, and model of care that spans the life course. The EBCD approach appears to be highly effective in addressing power imbalances, fostering eagerness to learn together, and to cocreate services improvements that have buy in from all three perspectives.

A Study of the Experiences of Youth in Returning to Education and Employment After a First Episode of Psychosis at a Montreal-Based Early Intervention Program

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Manuela Ferrari, *Douglas Mental Health University Institute*
Matthew Peters, *Douglas Mental Health University Institute*
Srividya Iyer, *Douglas Mental Health University Institute*

Background: Specialized early intervention services are designed to meet the needs of young people who are experiencing a first episode of psychosis. To promote recovery, early intervention services offer medication to cope with illness symptoms as well as psychosocial interventions, such as psychoeducation, family intervention, cognitive behavioral therapy, supportive psychotherapy, case management, and job skills training and education. A continuing challenge for early intervention services is the significant numbers of young people who do not attain adequate functional (work/school) outcomes. This project addresses this challenge. Objective: The objective of the present study is to shed light on the complex social and interpersonal processes involved in returning to work and school from the perspectives of young persons with psychosis, with a particular focus on those “not in education, employment, or training” (NEET). Method: A qualitative approach was used to examine how young people, who have received mental health services for a first episode of psychosis, think about work and school. We interviewed youths from a Montreal specialized early intervention service, who had been NEET for at least 6 months. We conducted individual in-depth interviews with five service users between 14 and 35 years old. Results: Four superordinate themes were identified from the data: (1) past experiences informed present self-schemas, (2) the importance of autonomy in fostering motivation toward work and/or school goals, (3) the importance of different forms

of support, and (4) the regeneration of a future identity as a step toward returning to work and/or school. Conclusion and Implications for Practice: The findings of this study suggest that the process of returning to work and school is part of a larger process of integrating past experiences and envisioning a future self in society. This process is ultimately part of a personal journey that should be fostered with social support of family, friends, mentors, and service providers. Such social support needs to be both practical and autonomy focused.

Reflections on Conceptualization, Visualization, and Technology Use in the Analytical Process

Daniel A. Nagel, *University of New Brunswick Saint John*
Alison Luke, *University of New Brunswick Saint John*

While conducting qualitative research, our memos and diagramming reflected the integration of conceptualization, visualization, and use of technology as key to our analytical processes. These integrated elements played a significant part in the development of the final theoretical model for “getting a picture,” a constructivist grounded theory study that highlighted use of mental imagery by nurses knowing the person in a virtual environment. Although there are many references to the use of gerunds and metaphors in the literature to give a sense of action or evoke an image of process in grounded theory and other research traditions, little has been written about the researcher’s use of mental imagery as part of the analytical process. We present a brief discussion of conceptualization as it relates to qualitative research and describe how visualization assisted us in conceptualization during the research process. We further outline three main aspects of conceptualization and visualization that stem from our research, including (a) How mental imagery can be viewed as an integral process to conceptualization, (b) the role mental imagery and visualization played in our analytical processes, and (c) how we employed technology as an adjunct to conceptualization and visualization in our studies. From our research experience and investigation of the literature, we propose that the capacity for mental imagery of the researcher may influence conceptualization and visualization in the process of analysis. We also believe that skills for conceptualization can be developed and enhanced with strategies such as use of technology.

“I Was Excited to Have My First Stretch Mark”: Adolescent Motherhood, Food, and the Body

Cara Ng, *Simon Fraser University*

While an abundance of studies suggest that young North American women have tremendous anxieties about food and their bodies, there is still a shortage of research describing the experiences of adolescent mothers as they relate to food

and body image. Qualitative research centering young mothers’ voices on this topic is even scarcer. This presentation is based on findings from a master’s thesis dissertation I completed in 2012. I conducted 10 semistructured interviews with adolescent mothers in the Lower Mainland of British Columbia, Canada, in 2011, with the intention of exploring what particular shape food- and body-related anxieties might take when adolescence overlays with motherhood. I used voice-centered methodology entailing multiple interpretative “readings” through each of the interview transcripts as a method of understanding various aspects of the participants’ narratives. This article illuminates one stage of the voice-centered methodology: reading for “contrapuntal” voices within participants—stories about their bodies. What I gathered from the narratives was that it was not uncommon for young mothers to discuss food- and body image-related issues in paradoxical ways. Analyzed through the lenses of intersectionality and feminist poststructuralism, themes of acquiescence, resistance, and contradiction were three key ways teen mothers interacted with dominant discursive constructions about eating and the body. I will preliminarily explore what these narratives suggest about dominant discourses regarding food and body image, as well as how these research findings can inform future policy and programming for young mothers, with an aim toward fostering healthy body image and eating behaviors.

A Thematic Analysis of Youth Descriptions of Family Resilience in Three Communities in Western Canada

Cara Ng, *Simon Fraser University*
Allie Slemon, *University of British Columbia*
Emily Jenkins, *University of British Columbia*

While the notion of resilience was first discussed in the medical sciences in the late 1920s, scholars in myriad disciplines such as ecology, psychology, urban planning, and geography have since taken a keen interest in its conceptual development. Early resilience scholars in psychology viewed resilience as an individual trait—a quality that one possessed or not—but the socioecological turn in resilience studies now contends that resilience is a process through which an individual navigates adversity within multilevel, complex environments. Family resilience, within this framework, is defined as a process through which family functioning is adaptive to systemic and environmental factors. Data from this presentation are based on the Researching Adolescent Distress and Resilience study, a multisite qualitative project that explored the social context of youth experiences with emotional distress and resilience. Using thematic analysis to interpret our findings, this presentation will elucidate the different ways youth described family resilience and how these might be connected to fostering or hindering their resilience. Interviews were conducted with 83 young people aged 13–18 years old from a diversity

of ethnoracial backgrounds in three distinct communities across British Columbia, Canada, from 2012 to 2013. We will conclude by looking at ways these findings might inform policies, programming, and practices that can help enhance experiences with resilience for youth both within and beyond the family context.

Learning on the Go: Conducting Participatory Action Research on Restrictive Measures in Long-Term Residential Care

Alistair Niemeijer, *University of Humanistic Studies*

Nienke Bekkema, *VU University*

Clasien de Schipper, *University of Amsterdam*

Brenda Frederiks

Recent reports show that use of restrictive (social, physical, and pharmacological) measures (RMs) is still a current theme in long-term residential care (LTC) and serious cause for concern, as service providers struggle with identifying potential risks and consequences. Professional caregivers including nurses (assistants) and support workers hold a key role in the (non)application of RM in the daily care of their clients and have valuable knowledge on dilemmas concerning the use of RM. Nevertheless, their role and perspectives in research on RM have so far been limited, which are partly caused by the fact that the application of RM is often considered a complex and contentious topic. A research approach that might be well suited to addressing complex and sensitive issues in LTC is participatory action research (PAR), as it adapts to local needs, delivering a tailored and collaborative approach to improving local practice. This presentation describes our (ongoing) PAR study in five LTC facilities in the Netherlands, whereby within each facility we formed a research team with eight caregivers and two to four researchers from the university. Even though we were all relatively experienced (qualitative) researchers, none of us had any prior experience with conducting a PAR study. This initially meant “learning on the go,” and although this lack of experience did result in several stumble blocks, which we will reflect upon, it also meant having a fresh perspective on both the merits of PAR and our understanding of RM itself.

When Is $N = I$ a Collective Experience? Patient Experience, Membership, and Qualitative Methodologies in Health Care

Alistair R. Niemeijer, *University of Humanistic Studies*

Merel Visse, *University of Humanistic Studies*

Even though in health-care policy and practices, patient experience is considered to be “the new heart of healthcare leadership,” it is questionable whether singular experience(s) can truly represent a collective experience of affected persons. Trends toward public accountability and patient empowerment tend to highlight the importance of patient involvement by

creating structural approaches to their inclusion, whereby patients are seen as members of a collective or peer group. However, not everybody wants to belong or be explicitly included in a specific (peer) group, the membership of which is considered by many as unfavorable. Furthermore, such “partnership in participation” is neither conceptualized nor operationalized. How then can we democratize the representational sphere of collective patient or client experience in health-care policy and practices (i.e., peer groups), without overlooking the particular experiences of individuals, which are potentially in tension with dominant discourse (cf. Neumann, 1996). In other words, how can particularity be acknowledged as an important entry point for including alterity in representation of voices in policy and research? This presentation aims to explore how methodologies (such as auto- and duo-ethnography, phenomenology, and narrative approaches) of (vulnerable) singular and insiders’ perspectives on experiencing living with illness and disability might provide such an entry point. Rather than trying to “capture” these perspectives or experiences, which could lead to “malconstructions” (cf. Lincoln & Guba, 1989) of people’s perspectives, we argue for an interactive, responsive, and relational approach to partnerships. This presentation is ultimately a critical endeavor to see whether and how particular experiential knowledge can be viewed as representational in the context of health-care partnerships and credible collective experience of affected persons.

Macro cognition in the Health-Care-Built Environment (m-HCBE): A Focused Ethnographic Study of “Neighborhoods” in a Pediatric Intensive Care Unit

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Emily Patterson, *The Ohio State University*

Jim Fackler, *Johns Hopkins University Hospital*

The three objectives of this research were to (1) describe a way to understand macrocognitive interactions, whether formal or informal, and learn where on a pediatric intensive care unit (PICU) these interactions occurred; (2) use the space syntax constructs of openness, connectivity, and visibility to describe challenges and facilitators of macrocognition; and (3) use those constructs to explicate influences on macrocognition to analyze the health care built environment (HCBE). Background: Macrocognition offers a whole system approach to develop new knowledge between interprofessional team members in complex industries such as health care. The effect of the HCBE on those functions has not been directly studied, although macrocognitive functions have been analyzed in multiple health-care settings. “Macrocognition in the health care built environment” (m-HCBE), a theoretical framework, addresses this relationship. Method: Observation and focus groups were conducted. Distance matrices and isovist field view analyses were created using architectural drawing files. This institutional review board–approved focused ethnographic study was conducted in a U.S. East Coast academic medical center.

Sample: Interprofessional team member participants were recruited for both observation and focus groups using maximum variation sampling. Data Collection Procedures: For 10 days, on the day shift, ethnographic field notes were manually recorded of unit observations in three PICU locations: corridors, support spaces, and outside patient rooms. Interprofessional team members were observed, and four focus groups were conducted. Panoramic photographs from each nurses' station were taken, and floor plans (architectural data files) were obtained. Analytic Approach: Ethnographic nonparticipatory field notes, verbatim transcribed audio recordings, panoramic photographs, distance matrices, and isovist (360 degree) field views were calculated (MS Word, Excel, and preliminary analysis using NVIVO). Directed content analysis, iteratively performed in three stages, allowed initial coding, comparisons, and addition of new emergent themes. Results: In this PICU, "neighborhood" configurations comprised of "corners," which provide the greatest visibility between key functional spaces, offer the optimal opportunity for informal macrocognitive interactions. Conclusions: In the health-care built environment, the complex link between space syntax constructs and macrocognitive interactions was demonstrated with this study. When considering renovating existing spaces or designing new spaces, the m-HCBE theory can provide guidance to incorporate configurations that provide the greatest opportunity for informal and formal macrocognitive interactions to improve patient safety and quality.

Co-Creation of a Community-Derived Elders Mentoring Program for Pregnant Cree Women and Their Partners: The ENRICH First Nations Study

Richard T. Oster, *University of Alberta*

Ellen L. Toth, *University of Alberta*;

Rhonda C. Bell, the ENRICH First Nations Community Advisory Committee, *University of Alberta*

Responding to concerns over perinatal health risks and adverse outcomes, a community-based participatory research (CBPR) partnership was established in collaboration with a large Cree community in Alberta, a neighboring primary care network, and university-based researchers. Following the direction of community members, considerable efforts were devoted to in-depth community engagement to build and enhance relationships and trust, to hear from community members, and to grasp the context in which pregnant women live. A Community Advisory Committee was subsequently established that identified an urgent need to address the lack of access to cultural and social support within the perinatal clinical setting. In response, a community-derived Elders Mentoring Program for pregnant women and their partners was conceived and implemented. The Program was piloted in Fall 2015, expanded in Spring 2016, and is ongoing. Elders engage with parents-to-be within the waiting area by striking up conversations, offering support, handing out Program flyers, providing healthy snacks and

beverages, conducting cultural activities and displays, and initiating draws for free traditional moss bag infant carriers. Those seeking additional elder support have the option of speaking privately in a separate room. The Program is currently being evaluated qualitatively, based on the principles of CBPR and utilization-focused evaluation. Initial findings suggest the Program builds off community strengths to provide a much needed platform for mutual learning leading to enhanced support networks for parents-to-be, a sense of fulfillment and enjoyment among Elders, and improved cultural understanding and sensitivity for clinic staff.

A Qualitative Study Into the Difficulties Faced by Indigenous Groups in Developing Countries When Accessing Health Care: A Case Study in Nicaragua

Andrew Papworth, *University College London*

A number of studies have investigated the utilization element of health-care access for Indigenous peoples, but most of this research has been conducted with Indigenous populations based in developed countries, principally Australia, the United States, and Canada. The research presented in this article is an attempt to begin addressing this imbalance and is based on a case study of the Rama who live on the Caribbean Coast of Nicaragua. It represents the first time access to health for this Indigenous group has been investigated. Research data come from one focus group and 31 semistructured interviews with both Rama individuals and non-Rama health professionals, conducted between May and June 2016. The article will first outline the present condition of health care on the Caribbean Coast, encapsulating both Western and traditional medicine facilities. The article will then describe the difficulties many Rama face with financial decision-making and explore how this affects their ability to access health care. Finally, it will briefly outline individual case studies to describe the structural barriers to health care that exist for the Rama. These are many and complex and include a lack of reliable health information, a shortage of Rama health professionals, poor retention rates for non-Rama staff, and the high price and low availability of medicines. The article will conclude by highlighting the heterogeneity of Rama health-care experiences and through drawing on the cultural safety and health inequality literatures by outlining potential solutions.

Falling in Love and/or "A Pain in the Ass": A Qualitative Study of Medication Adherence in First Episode Psychosis

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Manuela Ferrari, *Douglas Mental Health University Institute*

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Medication adherence, taking medications as recommended, affects the success of psychosis treatment. Quantitative studies

have found a number of factors that affect adherence including implicit attitudes toward medication. The experiences of patients taking medication have, however, only just begun to be examined qualitatively and patients' attitudes toward medication, as well as what shapes these, are still under studied. This embedded case study explores medication adherence of patients at an early intervention program for psychosis, Prevention and Early Intervention Program for Psychosis-Montreal. Five clients' journeys are used as embedded units within this case study. Prior to receiving treatment, attitudes toward treatment seemed to be affected by their own past experience or that of their families' with medication and/or chronic illness. Families' attitudes toward mental health and medications were more important than significant others' or friends'. Changes in medication, experiences with different treatment models and clinicians, and periods of nonadherence all influenced participants' attitudes toward medication. All participants reported periods of nonadherence and most reported a fear of relapse and further hospitalization as a motivation for continuing adherence, though side effects presented a significant deterrent to adherence. This study's findings can improve clinicians understanding of the implicit attitudes which influence clients' medication adherence. The use of an embedded case study design allowed us to uncover the conditions which determine medication adherence and how context shaped these attitudes.

An Early Integrated Palliative Care Approach for Patients With Idiopathic Pulmonary Fibrosis: Experiences of Bereaved Family Caregivers

Charlotte Pooler, *University of Alberta*

Idiopathic pulmonary fibrosis is an incurable lung disease, with an unpredictable and potentially rapid trajectory. Both patients and caregivers experience a distressing and high symptom burden. Palliative care is recommended but rarely utilized, and most patients die in hospital. A narrative approach was used to explore bereaved family caregivers' experiences and perceptions of an early integrated palliative care approach implemented at a multidisciplinary interstitial lung disease clinic. Eight participants shared their stories in open-ended interviews. Thematic and content analysis was used, and their stories reconstructed. There were five major themes: having a terminal disease, planning goals and wishes for care, living life and creating memories, feeling strain and responsibility, and nearing the end. Participants started with moments of recognizing the disease as terminal. They were enabled to know and support patients' goals and wishes and have quality of life and meaning in the time remaining. Caregivers expressed needs for additional support services and respite. They felt prepared and supported when death was near. Alleviation of

both fear and symptom distress was integrated across themes. These bereaved caregivers advocated for an early palliative care approach in and through their stories. They did not express distress or anxiety related to relationship strain or symptom burden as described in the literature. Collaboration and close communication among patients, caregivers, respirologists, and home care staff were essential for perceived quality of life, death and dying, and bereavement. Practice and policy considerations for an early integrated palliative care approach are of importance for this population.

The Role of Qualitative Research in Intervention Development to Improve Nurse-to-Nurse Shift Handoff Communication

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The World Health Organization identifies communication during patient handoffs as a leading cause of patient safety sentinel events. Although a standardized approach to handoff communication is recommended, a structured approach may not change habituated communication practices. Most evidence of end of shift handoffs involves physicians, leaving nurse-to-nurse handoff communication less often investigated directly. This mixed-methods study examined the communication interactions between professional nurses during end-of-shift handoffs on in-patient units in one U.S. Veterans Affairs medical center. Relational coordination theory serves as an effective means to classify and explain the behaviors of health-care professionals during a cycle communication that characterizes relationships in this type of speech event. To bridge the gap between practice and nursing practice change, 36 nurse shift handoffs in three medical-surgical units at one hospital site were recorded, transcribed, and coded, using the type of discourse analysis called interactional sociolinguistics. The World Bank's Human Development Network provided a framework used to identify quality for performance improvement. Discourse patterns associated with positioning, engagement, and social identities were compared to scores from a standardized tool, the Handoff CEX, applied to recordings by two raters. Results were integrated to create a matrix of areas for improvement, proximal objectives, potential project activities in response, context determinants to be addressed, and an implementation plan, structured by response to qualitative findings. Follow-up nursing feedback from focus groups reflecting on anonymous transcript excerpts provided final benchmarks for intervention mapping of a training intervention for nurses to be tested in a future study.

Who Should Be Responsible for Supporting Individuals With Mental Health Problems? Perspectives of Multiple Stakeholders

Megan Pope, *Douglas Mental Health University Institute*
 Shruthi Venkataraman, *Douglas Mental Health University Institute*
 Ashok Malla, *Douglas Mental Health University Institute*
 Srividya N. Iyer, *Douglas Mental Health University Institute*

Individuals with mental health problems, particularly those with serious mental illnesses like first-episode psychosis (FEP), have many inadequately met support needs. Relevant stakeholders' perceptions of who should be responsible for meeting these needs remain unexplored; yet varying perceptions could contribute to unmet needs within this group. We sought to explore the views of youth with FEP, their families, treatment providers, and mental health policy/decision makers as to who should be responsible for supporting individuals with mental health problems and to discover what responsibilities they assign to these parties. Using a qualitative descriptive design, focus groups were conducted with youth with FEP, families, and treatment providers from an early psychosis intervention program in Montreal, Quebec. Individual interviews were conducted with mental health policy/decision makers. Transcripts were analyzed thematically. Participants assigned a range of responsibilities to individuals with mental health problems, stakeholders in the immediate and extended social networks of these individuals (e.g., families), macrolevel stakeholders with influence (e.g., government), and society as a whole. The need for greater sharing of responsibilities among stakeholders and perceived failings of the health-care system also emerged as important themes. Participants largely agreed on the roles and responsibilities of key stakeholder groups, suggesting that health-care system failings may be more likely contributors to unmet support needs than varying perceptions. Our findings also suggest that various stakeholder groups with different levels of influence can and should collectively assume certain responsibilities. The implications of this study for shaping mental health policy, services, and future research will be discussed.

Improving Health and Community Well-Being With Big Data in the UK: Citizens in the Driving Seat?

Carol Porteous, *University of Manchester*
 Mary Tully, *University of Manchester*
 Sarah Cunningham-Burley, *University of Edinburgh*
 Mhairi Aitken, *University of Edinburgh*

The UK has a programme of funded "big data" research initiatives (Farr Institute, Administrative Data Research Network and Connected Health Cities). While focused on using routinely collected data from health and public authorities to improve health and social well-being, these initiatives are not without challenges. The "big data" used by the research

initiatives are largely used without consent. Recent highly publicized controversies relating to such data uses have resulted in the need to understand publics' perceptions and preferences to try and pursue research that proceeds in ways which reflect public interests. This presentation reports from a program of qualitative research including citizens' juries, deliberative workshops, and panels, which have involved publics and citizens to explore the acceptability and public interest of using routinely collected data in research. It is clear that while some citizens may be reticent about their data being so used, our evidence suggests that publics may be supportive and indeed may even be a driving force of this research. In bringing the tensions in understandings to the fore, our research highlights the importance of understanding public perspectives in order to facilitate the pursuit of publicly beneficial research. Through meaningful involvement of publics and citizens in qualitative research in health and social informatics, we can demonstrate the importance in securing the role of the publics in order to pursue ethically and socially relevant research which realizes public benefit for citizens.

Overcoming the Difficulties of Inclusion of Linguistic Minorities in Qualitative Health Research: Lessons From Occupational Health

Stephanie Premji, *Institute for Work and Health*
 Agnieszka Kosny, *Institute for Work & Health*
 Basak Yanar, *Institute for Work and Health*
 Momtaz Begum, *Access Alliance*
 Dina Al-Khooly, *University of Waterloo*

Canada is increasingly multilingual. Currently, one in five Canadians report a nonofficial language as mother tongue, and this proportion is projected to rise to one in three over the next two decades. Individuals with a nonofficial language as mother tongue fall along a wide continuum of verbal and written skills in the official languages, allowing them to function effectively or ineffectively, based on skills and context. This language proficiency, or lack thereof, is an important social determinant of health. Yet linguistic minorities are largely absent from qualitative health studies, in part because of the practical difficulties associated with their inclusion. Drawing on multiple qualitative research projects conducted by the authors in the field of occupational health in Toronto and Montreal, we discuss the difficulties of inclusion of this population at different stages of the research process and propose practical strategies to overcome them. Namely, we discuss challenges and strategies related to the research question, study design, recruitment, data collection, analysis, dissemination, and ethics, including issues of informed voluntary consent and the fair distribution of benefits and burdens. We further address the funding challenges associated with research involving this hard-to-reach and hard-to-study population and discuss the role of funders and publishers in advancing the goal of fairness and equity in health research in general and occupational health research in particular. This presentation is linked to the one submitted by

Dr. Kosny: “Implications of exclusion: immigrant, work, and health research.”

Creating a New Work Reality: A Meta-Ethnography of Research Exploring Multiple Sclerosis and Employment

Rebecca Purc-Stephenson, *University of Alberta*
Hailey Smith, *University of Alberta*
Jessica Dostie, *University of Alberta*

Multiple sclerosis (MS) is a chronic, disabling disease of the central nervous system that is often diagnosed between the ages of 15 and 50 years. Symptoms range from mobility impairments and fatigue to neurocognitive impairments of verbal fluency, information processing speed, and memory. These symptoms can seriously disrupt the working lives of persons with a multiple sclerosis (PwMS), who now may be limited in the work they can do, may require workplace accommodations, or experience discrimination. Our goal was to understand how PwMS experience employment after diagnosis and to use this information to build a conceptual model that describes what they need to sustain employment. We searched published studies on MS and employment from six electronic databases (1980–2017) and bibliographical reviews using a combination of keywords related to MS, employment, and qualitative research. Our search yielded 274 articles, and after applying the inclusion criteria, 13 studies were retained. Two reviewers independently reviewed, critically appraised, and extracted concepts from each study in chronological order. Using a meta-ethnographic process, we identified 10 themes highlighting the common issues experienced by PwMS. Using these themes, a process model was developed that illustrates how an MS diagnosis triggers a work-specific identity change and then motivates an individual to create a new work reality for themselves. This new work reality is facilitated by social support, workplace accommodations, disclosure, and symptoms management. This study provides a framework to help rehabilitation specialists, employers, and researchers understand what PwMS may need to sustain meaningful employment outcomes.

Challenging Narratives of Loss: Constructing the End-of-life Experiences of People With Advanced Dementia

Gloria Puurveen, *University of British Columbia*

Current research that examines end-of-life (EOL) care for people with advanced dementia is predominated by a biomedical discourse that constructs a storyline along narratives of loss, deterioration, and decline of the body, which obscures relational and spiritual elements of the dying experience. If we accept that the EOL is more than an experience of a deteriorating body, then research must take a holistic perspective and offer a counternarrative that attends to the depth of human experience. This article presents findings from ethnographic

case study research exploring how nursing home-care staff and family understood the needs and experiences of two women with advanced dementia nearing the EOL. In-depth interviews with 23 staff (nursing, management, and allied health) and two family members, over 500 hr of participant observation, and 30 hr of video observation were conducted in one nursing home. Informed by a dialogical perspective, thematic analyses revealed that while care-staff’s and family’s reflections were ungirded by a storyline of deterioration, their narratives foregrounded an ethical commitment toward the residents that went beyond the boundaries of fulfilling instrumental tasks and caring for the dying body. Care staff and family sought to nurture their relationship with the residents; through a deep understanding of the residents, they acknowledged the residents’ personhood; and they skillfully provided empathetic and responsive person-centered EOL care while negotiating structural barriers (e.g., workload). These findings have important implications for practice and education of care providers and have important implications for challenging the dominant discourse of dementia as loss.

Identifying a Potential Solution for Overweight Urban and Rural Military Reservists

Courtney M. Queen, *Texas Tech University Health Sciences Center*
Lex Hurley, *Texas Tech University Health Sciences Center*

Learning Objectives: Identify perceived barriers to weight loss and maintenance in Marine Corps Reserves Members. Discuss statements from focus groups with Reserve Marines on the Body Composition Program. Background: United States Marine Corps (USMC) reservists are volunteer and only present on a military base one weekend per month. If any reservist falls outside of military weight/height standards, they can be assigned to probationary Body Composition Program (BCP) and face military discharge if sufficient weight loss is not achieved. A lieutenant in charge of a USMC unit contacted investigators to determine potential solutions and reduce drop-out of reservists. Design and Method: A mixed-methods investigation was conducted by distributing a qualitative survey instrument to the entire reserves unit ($n = 78$) and gathering overweight BCP ($n = 18$) members for an hour-long guided focus group to determine such constructs as perceived barriers and facilitators to weight loss, perceived social support, and self-efficacy. Relevant areas of surveys and transcripts were conducted under the lens of the health belief model, trans-theoretical model, and social ecological models for BCP members. Results: While there were no significant differences in survey results between overweight and nonoverweight reservists, the focus group revealed BCP reservists’ perceived barriers include: frequently struggling with working multiple part-time jobs and overnight shifts, binge eating, and an overreliance on prepared foods from fast-food venues and

convenience stores due to perceived time constraints. Participants vigorously pursued increasing their physical activity by neglecting sleep and often exhibiting low self-efficacy for increasing nutritional quality of diets due to lack of health knowledge. Social support for BCP members was low, as all lived isolated from other reservists, often in rural areas, and with nonmilitary housemates. All BCP members specified declining motivation over time, yet viewed their overweight as self-centric and resigned to independently solve their problem in isolation. Conclusions: Investigators proposed an extended duration mobile health intervention with a group chat to connect both urban and rural reservists and address low scores of social support and isolation. Further, to address low scores of self-efficacy for increasing nutritional quality, investigators will deliver tailored health messages promoting beneficial health behaviors as well as information to increase participants' health knowledge.

Collision of Worlds—The Lived Experience of Nurses Who Care for Family Who Are Chronically Ill: A Heideggerian Approach

Loretto Quinney, *Central Queensland University*
Trudy Dwyer, *Central Queensland University*
Ysanne Chapman, *Independent Scholar*

When a person with chronic illness is admitted to hospital, they often have a family member to support them during exacerbations of the disease. When the person is also a registered nurse, the ally becomes doubly equipped; providing professional knowledge together with personal understanding that enables the gathering of resources and contacts so that care provision can be optimized and individualized. Previous literature about carers for the chronically ill is dominated by discussion around the burden of caring, and considerable investigation of this aspect has been published in social, political, and industrial arenas. Additionally, there is growing recognition that partnerships with consumers are essential to the improvement of health-care design and delivery. However, there is a gap in our understanding of the contribution that carers make to seamless care provision for the chronically ill as they move through acute health-care systems. Registered nurses who care for a family member with chronic illness are in an unparalleled position to critique and contribute to health care. Nurses who are family carers have experienced exposure to the health-care system from professional and personal perspectives, and the extensive knowledge that is built from these involvements has not previously been explored. This presentation examines the findings from a hermeneutic phenomenological study involving 15 registered nurses from two states of Australia. Conversational interviews were used to enable participants to share their experiences of “being” a carer for a family member during acute exacerbations of chronic illness. The analysis used Heideggerian phenomenology to identify three overarching themes of personal, professional, and

practical understanding to illuminate the lived experience of being a nurse with an ongoing responsibility to care for a chronically ill family member.

“It Works, But It’s Difficult”: Patients’ Experiences and Perspectives of Treatments for Obstructive Sleep Apnea

Tamara Rader, *Canadian Agency for Drugs and Technologies in Health*
Sarah Garland, *Canadian Agency for Drugs and Technologies in Health*

Obstructive sleep apnea (OSA) is a sleep disorder in which breathing repeatedly stops and starts when the throat muscles relax. If left untreated, OSA can lead to cardiovascular problems, motor vehicle accidents, and difficulties with work or family life. Almost 3% of Canadians have OSA; however, guidance concerning the optimal use of treatments for OSA, which includes weight loss, oral appliances, continuous positive airway pressure (CPAP), or surgery, is needed. To inform the development of pan-Canadian recommendations on the optimal use of OSA treatments, a systematic review of qualitative studies was undertaken in 2016 to describe the treatment experiences and perspectives of adult patients and their bed partners. Thirty-two qualitative studies were included, and two analytic themes were derived from a thematic analysis of the studies. Patient factors that influence OSA treatment are individualized and contextual. People consider the trade-off between the benefits of OSA treatment versus their discomfort with the intervention. For some patients, feelings of discomfort were enough of a deterrent that therapy was discontinued. For others, the physical, mental, and social benefits were motivation to continue, and discomfort decreased as patients became accustomed to the device. For those using CPAP, the sense of embarrassment and perceived unattractiveness while using the device might be a reason for discontinuation. Patient experiences of treatment are multifaceted, involving not only their own experience but the experience of their partner. Decisions regarding treatment may be made within the context of their relationship. Gender and socioeconomic factors also influence treatment experiences.

Construction of Rape Cyborgs in a Digital Post-Human World in Dhaka

Laila Rahman, *University of Toronto*

According to Haraway, a cyborg is not born but generated from an infusion of human and technology. In this project, using Haraway’s cyborg concept, I invoke a new identity of “rape cyborgs,” who inscribe their rape acts in videos of their own making. This inquiry has been invited by a media outburst against two affluent men’s recording of their raping of two females at gun point in a high-end hotel in Dhaka. Their act of recording the rape incident indicates these men’s

fetishizing over the digitization of rapes in which they construct themselves in control of their victims by way of using another technology as an extension of their manhood, a gun. The technologies of money and social capital are also embedded in their cyborg identities. Despite the presence of other technologies, I argue that their use of digital media ultimately takes these men to their posthuman world and creates them as rape cyborgs. As the story unfolds, these men wanted to wield indefinite control over their victims with a threat to circulate their rape videos on social media. Little did they know that their victims would resist as survivors and bring their story of resistance into the public domain. A post-colonial feminist discourse analysis of 107 online news reports indicates the fluidity of representation of these men from mere human rapists to rape cyborgs and of these women from the “other” to the other which, in turn, put their identities in flux between victims and survivors.

“Drinking the Kool-Aid,” “Selling Seats,” and “Cones of Silence”: Engaging Diverging Perspectives in a Focused Ethnography of the Implementation of a Provincial Suicide Prevention Initiative

Patti Ranahan, *University of Victoria*

Jennifer White, *University of Victoria*

In response to increasing rates of deaths by suicide, the province of British Columbia funded the implementation of a standardized suicide prevention gatekeeper training initiative with the aim of training 20,000 citizens between 2015 and 2018. Implementation processes of population health initiatives are complex and messy and often involve adaptations and compromises in order to meet local community needs and competing demands. Further, the distinct perspectives, differing levels of investment, and creative endeavors of multiple stakeholders in such large initiatives can remain in the shadows of measured achievements toward the end goal of training several thousand citizens. In this micro-oral presentation, the researchers offer insights into designing an ethnographic research approach that works to meaningfully engage stakeholder participants at varying levels of experience, participation, and investment in health initiatives. A relational constructivist framework is used to analyze data derived from interviews with policy makers, provincial and regional decision makers, and representatives from community organizations with vested interests in suicide prevention, gatekeeper trainers, and workshop participants, along with document analysis and field/participant observations. Description of this analytical framework will be offered using an example of our analysis of initial data, in which “drinking the Kool-Aid,” “selling seats,” and “cones of silence” were explanations of early relational realities that are (re)constructing the realities and relations in the implementation process.

Exploring Long-Term Patient Satisfaction With Total Knee Arthroplasty

Ellen Randall, *University of British Columbia*

Laurie J. Goldsmith, *Simon Fraser University*

Stirling Bryan, *University of British Columbia*

Total knee arthroscopy (TKA) is the highest volume joint replacement surgery in Canada, yet studies find that 15–20% of patients are not satisfied post-TKA. Policy makers, clinicians, and researchers, therefore, need to advance their understanding of TKA patient satisfaction. Given the implant is designed to deliver long-lasting benefits, identifying factors affecting long-term satisfaction will build on the current knowledge base and offers the possibility of uncovering service transformation opportunities. Using a patient-centered care lens and grounded theory, we explored factors associated with long-term patient satisfaction following primary TKA surgery. Twenty-seven patients were interviewed, 3–4 years following surgery. Purposeful sampling was undertaken from a cohort of patients who had completed a TKA satisfaction survey administered at 3 years postsurgery. Key sampling characteristics included sex, region, self-rated satisfaction, and pain and function scores. Patients who were not satisfied were oversampled. Semistructured interviews were analyzed to identify key categories and their relationships. Adaptation to the knee replacement and its role in one’s life over the years following surgery emerged as the central category. Variation in adaptation was evident within subcategories including (1) easy assimilation of an implant that brought full symptom relief and renewed functionality, (2) willing acceptance of improvement, despite less than perfect outcomes, and (3) de-emphasis on the TKA within a broader context of more pressing life circumstances and health issues, and (4) an ongoing central focus on the TKA because of severe unresolved knee-related issues. This presentation will characterize the concept of adaptation and elaborate on its supporting themes.

Insights From Researching Ethnic, Sexual, and Gender Minority Youth: Ethical Concerns Regarding Qualitative Research With Vulnerable Populations

Jishian Ravinthiran, *McGill Department of Psychiatry*

Srividya Iyer, *McGill Department of Psychiatry*

Lucie Nadeau, *McGill Department of Psychiatry*

A proposal to explore the struggles of Asian Immigrant Lesbian, Gay, Bisexual, Trans and Queer (LGBTQ) youth and associated barriers to social support and mental health service use underwent an institutional review process and numerous ethical concerns arose. Some of these concerns derived specifically from the use of a qualitative methodology with a vulnerable population for whom parental consent could not be feasibly attained. Insights that will be disseminated to other researchers in this presentation include a forewarning of the challenges that may arise during the ethical review of qualitative research proposals

regarding vulnerable youth; for example, how qualitative interviewing methodologies may be perceived to possess greater inherent risks relative to the impersonal nature of quantitative measures. By implication, this can preclude critical qualitative research as, in the Canadian context, legislation imposes stringent restrictions regarding acceptable risks in conducting research with minors. Crucially, this presentation will inform other researchers of alternative safeguards and the logistics of their implementation, thus mitigating these concerns related to risk. This presentation is also intended to draw attention to the central lesson of this process: How science, though intended to benefit individuals equitably, can propagate harm by categorically excluding certain perspectives from research seeking to inform the development of evidence-based services, namely, the perspectives of vulnerable youths who need competent services. In spreading awareness of these issues and pragmatic solutions to researchers and institutional review board members alike, we hope to aid in ensuring research does not fail those most in need of its benefits.

From Romance to Violence: An Interview Study of Female Highschool Seniors With a Long Trajectory of Dating Aggression

Patricia M. Reeves, *University of Georgia*
 Pamela Orpinas, *University of Georgia*

Healthy teens is a mixed-methods, longitudinal study of teen dating violence (TDV), funded by the Centers for Disease Control and Prevention, that followed a cohort of 657 students in Northeast Georgia from 6th to 12th grade. Every spring, students completed a survey about physical and psychological violence (victimization and perpetration). We identified students who consistently reported high levels of TDV across the 7 years. Because extant research reveals females are more likely to report interpersonal violence, we invited 12 females (8 Black and 4 White; randomly sampled and racially representative of the student population) to participate in 60- to 90-min individual interviews. The purpose of the study was to understand the process of dating violence, how it starts, develops, and ends, among female high school seniors who have a long trajectory of dating aggression. Data, analyzed using the constant comparative method, revealed the following process: The romance, short in duration, is characterized by euphoric emotions, caring behaviors, and frequent communication (multiple times a day). A period of transition, variable in length, follows where relationship dissatisfaction surfaces and signs of conflict emerge. Growing dissatisfaction provides fertile ground for jealousy, which spawns accusations of infidelity (peers play a prominent role) and controlling behaviors. This intensely emotional time is followed by disequilibrium, which manifests as loss of independence, loss of control, and loss of trust. Subsequently, violence ensues and is followed by regret (mainly) and shame (to a lesser degree). These findings, depicted in a detailed model, would be of interest to a multidisciplinary audience.

Methodological and Ethical Issues in Conducting Focus Groups With Adolescents

Patricia M. Reeves, *University of Georgia*

Collecting complementary data in a mixed-methods study presents methodological and ethical challenges that are important to consider during the design of a research study. These challenges were illuminated during the collection of focus group data in Healthy Teens, a mixed-methods, longitudinal study of social competence development and dating violence in a cohort of 657 high school students who attended eight high schools in Northeast Georgia. Healthy Teens is a follow-up study of the Georgia students who, during middle school, participated in GREAT Schools and Families, a multisite (four U.S. states) violence prevention program. Both studies were funded by the Centers for Disease Control and Prevention. The Healthy Teens research team conducted 44 focus groups. Each focus group included 6–10 students, randomly selected within gender groups, and lasted 45–60 min. Participants were randomly selected to enhance generalizability of the findings to the larger population of students. This sampling strategy, however, highlighted methodological concerns that would be viewed as limitations of the study. Chief among them is that in failing to consider how certain factors (e.g., racial/ethnic composition of the group) can influence the candor of participants, random sampling may limit the collection of information-rich data. Randomly sampling may pose an even greater concern when the sample comes from a vulnerable population (e.g., minors), and the topic for discussion is considered sensitive (e.g., dating violence). Concurrent with methodological issues are ethical concerns as well (e.g., possibility of including both the victim and perpetrator in a focus group).

In This Together: Relational Accountability and Meaningful Research and Dissemination With Youth

Jenny Reich, *Eskasoni Mental Health Services*
 Linda Liebenberg, *Dalhousie University*
 Mallory Denny, *Eskasoni Mental Health Services*

This presentation will explore what it means to engage youth in meaningful dissemination of research findings. To do so, the authors a group of academic researchers and community service providers will consider their experience working together with youth collaborators, aged 14–18 years, on the Spaces and Places research project, a participatory visual methods research program that took place in Eskasoni, a Mi'kmaq community in rural Nova Scotia, Canada. Over the course of the project, we developed a strong sense of relational accountability. Reflecting on our experiences, we believe that this is central to the development of a dissemination process that is meaningful and engaging. To reflect on youth perspectives and experiences of the project's dissemination process, we used a participatory action research technique—the Socratic Wheel—to examine six factors that contribute to a meaningful dissemination process: the degree to which the project is relationship building, strengthening,

rewarding, able to reach our intended audience, provides opportunities moving forward, balances structure with flexibility, and allows youth to have a sense of ownership over their work.

Barriers and Facilitators to Use of a Maternal Newborn Audit and Feedback System in Ontario: A Case Study Comparison

Jessica Reszel, *Better Outcomes Registry & Network (BORN) Ontario*
Holly Ockenden, *Better Outcomes Registry & Network (BORN) Ontario*

Sandra Dunn, *Better Outcomes Registry & Network (BORN) Ontario*

As part of a study examining the effectiveness of an electronic audit and feedback system (Maternal Newborn Dashboard [MND]) to improve maternal–newborn care practices and outcomes, we conducted a case study comparison of a diverse group of hospitals in Ontario. Our goal was to improve our understanding of factors that explain variability in performance post-MND implementation. A purposeful sample of diverse hospitals with varying success improving rates on MND key performance indicators (KPIs) was identified. Obstetrical director/managers were contacted to invite sites to participate in a 1–2 day visit by the research team. Site visits comprised (i) interviews/focus groups using a semistructured interview guide with nurses, physicians, leadership, and key personnel involved in clinical change processes and (ii) observations and document review. Interviews/focus groups were audio recorded and transcribed verbatim. Qualitative content analysis was used to code and categorize the data. Between June and November 2016, we visited 13 maternal–newborn hospitals and spoke with 107 individuals. Numerous factors contributed to the varying success of sites in facilitating practice change on KPIs. Hospitals successful in making changes on KPIs described facilitators including (i) useful features of the MND, (ii) trusting the evidence, and (iii) positive team characteristics. Hospitals with less change on the KPIs described barriers including (i) lack of alignment between KPIs and organizational priorities, (ii) lack of resources to implement changes, and (iii) challenges using/understanding the MND. These identified barriers and facilitators will inform strategies to improve the design and use of the MND, facilitating evidence-based maternal–newborn care.

Barriers to Cervical Cancer Screening Faced by South-Asian Muslim Immigrant Women in Calgary: A Qualitative Study

Syeda Kinza Rizvi, *University of Calgary*
Rebecca Malhi, *University of Calgary*
Marilynne A. Hebert, *University of Calgary*
Bejoy Thomas, *University of Calgary*
James A. Dickinson, *University of Calgary*

South Asian immigrant women are less likely to participate in cervical cancer screening compared to other immigrants and

nonimmigrants. Many of this subpopulation are Muslims. Understanding their ideas and needs may enable development of programs and services, so they can benefit from screening and reduce the effects of cervical cancer. We interviewed a sample of South Asian Muslim immigrant women in Calgary to identify the barriers that prevent them from having a Papanicolaou test. Snowball sampling was used to recruit South Asian Muslim immigrant women in Calgary, who had not been screened or infrequently screened for cervical cancer. We conducted qualitative, semistructured, in-depth interviews. Data were analyzed using thematic analysis. Eighteen women were interviewed: The majority (66%) had never had a Pap test. Barriers to cervical screening were divided into three categories: health-care provider, health-care system, and personal barriers. Provider and system barriers included lack of communication by health-care providers, limited access to female physicians, miscommunication by health-care system, and transport. Personal barriers included lack of knowledge about cervical cancer and screening, views and beliefs about cervical screening, including previous painful Pap tests, role of family and language. Strategies are needed at the system and provider level to promote cervical cancer screening. More skilled female physicians, increasing knowledge about cervical screening, providing resources such as transport, and screening reminders that explain the disease and procedure in detail could potentially increase screening practices among South Asian Muslim immigrant women.

Swimming Upstream: Building Qualitative Methods in a Quantitative Environment

Pamela Rothpletz-Puglia, *Rutgers University*

Health science researchers and funding institutions are increasingly recognizing the importance of patient and stakeholder engagement for understanding why and how an intervention can be successfully implemented. Health researchers predominately trained in the quantitative paradigm are finally acknowledging the importance of qualitative methods for formative research, patient-centered outcomes research, implementation science, and in mixed-methods projects. This endorsement of qualitative methods in health research is both exciting and welcomed. However, building qualitative research skills with health researchers primarily familiar with quantitative methods can be challenging. This Golden Nugget presentation will include the context and temporality of lessons learned from facilitating interprofessional health sciences faculty and student projects that incorporated qualitative methods. Several examples of projects with qualitative methods will illustrate methodological compromise, training and adoption strategies, accelerators and detractors for adoption, assimilation gaps, and future plans for increasing successful adoption of qualitative methodology into health research and curriculum.

Stakeholders Deliberative Panel Contributions Toward Refining a Protein-Energy Wasting Model for Research in Chronic Kidney Disease

Pamela Rothpletz-Puglia, *Rutgers University*

Emily Peters, *State University of New Jersey*

Laura Byham-Gray, *State University of New Jersey*

The International Society for Renal Nutrition and Metabolism formulated a model that theorizes etiological factors which may negatively impact nutritional status. This protein energy wasting (PEW) model is based on a comprehensive synthesis of available research but does not integrate the patient's perspective. Since this PEW model informs research development, we sought to engage stakeholders, patients living with Stage 5 chronic kidney disease (CKD) on maintenance hemodialysis (MHD), and health-care providers caring for patients with CKD, in panel discussions to deliberate the specific factors that are stronger determinants of PEW. Deliberative methods and the Patient-Centered Outcomes Research Institute engagement rubric and principles provided the framework and underpinnings that guided the stakeholder engagement. The stakeholder engagement included three deliberative panel discussions with patients living with CKD and three deliberative panel discussions with health-care providers caring for patients living with CKD. At the first meetings, stakeholders in both deliberative panel groups were provided with a blank PEW model. Every meeting resulted in a PEW model product that participants deliberated on through collective problem-solving. The PEW model was consecutively built upon and refined through deliberative problem-solving at each meeting, and a final stakeholder planning meetings are scheduled to present the outcome of this evidence prioritization planning phase. Since stakeholder-engaged research is becoming more commonplace and is recognized as desirable in study design, this presentation will focus on the deliberative methods used for the stakeholder engagement process.

Experience Level and End-of-Life Conversations: Barriers Encountered by Nephrologists and Nephrology Fellows

Jennifer St. Clair Russell, *Duke University*

Andrea Oliverio, *University of Michigan*

Amber Paulus, *Virginia Commonwealth University*

Not all treatments are appropriate for all individuals with kidney failure. Studies suggest conversations surrounding end-of-life decisions occur too late in the disease process or not at all. We sought to identify perceived barriers to end-of-life discussions among nephrologists and nephrology fellows to determine whether barriers differ by experience level. We conducted semistructured telephone interviews

with seven U.S. community-based nephrologists and seven nephrology fellows. Interviews were recorded and transcribed. Transcripts were coded by the principal investigator, a nephrology fellow, and a nurse, identifying major themes. The team met to review results, discuss discrepancies, and reach final consensus. Consistent themes emerged within each group, indicating thematic saturation. Barriers spanned multiple domains (i.e., personal, interpersonal, and system) with most consistent across both populations, regardless of experience level. For example, personal barriers included a "lack of a script" to use with patients. Interpersonal barriers focused on relationships with patients and families as well as other providers. The length of time treating a patient, either too short or a long-term relationship, was cited as a considerable barrier among both groups. Lack of time as well as a lack of privacy within dialysis facilities was cited as system barriers. Fellows faced unique barriers related to their position as trainees, such as lack of support from attending physicians. Further exploration is necessary to determine whether certain barriers are more profound based on experience level. Such findings can inform the development of targeted interventions by experience level (i.e., medical school training or continuing medical education).

Rigor in the Research Process: A Bicultural Researcher's Experience of Data Collection and Analysis in Arabic

Jordana Salma, *University of Alberta*

Researchers continue to engage in research activities with ethnically and linguistically diverse populations in the Western context to identify and address health inequities. This has drawn attention to the need for methodologically sound tools to ensure rigorous research processes and outcomes across linguistic and cultural mediums. This presentation will highlight considerations for data collection and analysis using the experience of an interpretive descriptive study on the health of Arab immigrant women. Sixteen women participated in semistructured interviews and completed health questionnaires in the Arabic language. Transcription and data analysis commenced in Arabic, with final translation of themes and exemplars into English. Languages are embedded within a cultural and historical conceptual universe; the use of a particular language influences the meaning making processes in research. Differences in function and expectations around language, especially, impact qualitative research approaches that depend on interviews as a primary data source. This presentation identifies lessons learnt from the perspective of a bicultural researcher focused on ensuring rigor, while acknowledging the messiness and complexity of capturing language and cultural nuances in the research process.

Qualitative Work Nested in Larger Clinical Trials: The Problem and Potential Bonus of Concurrent Recruitment

Elizabeth Sanderman, *Flinders University*
Sheryl de Lacey, *Flinders University*

In 2011, I began work as a research associate for a qualitative study nested in a randomized controlled trial of acupuncture to improve birth outcomes for women undergoing in-vitro fertilization (IVF) treatment. The trial involved IVF patients from different clinical sites around Australia and New Zealand. The qualitative study used in-depth interviews to explore what participants experienced when they had acupuncture done and how they thought acupuncture might help them. For the Gold Nugget presentation, we will share our experience with concurrent recruitment. For this presentation, we are defining concurrent recruitment as recruitment of one participant or group of participants to two related but different studies at the same time. Concurrent recruitment makes sense and may be necessary when clinical trials are accompanied by a qualitative study due to the complicated logistics of fitting a qualitative research piece within the confines of a trial which is usually happening in the presence of a sometimes complex medical condition or treatment. We will highlight potential pitfalls of concurrent recruitment that we discovered during the course of this study including overwhelming participants in the recruitment phase of the study(ies), having too many potential participants, and recruiting the wrong participants. However, due to a large sample size, concurrent recruitment contributed significantly to the study by resulting in a robust sample. From the experience of this study, concurrent recruitment for a qualitative study nested within a clinical trial can be successful, but researchers may need to seek out a large sample size to help overcome potential pitfalls.

A Decade of Engagement With Individuals as Well as Parents of Children With Rare Conditions: Reflections on Practice, Research, Actions, and Outcomes

Caroline Sanders, *University of Northern British Columbia*

The privilege of working as a children's nurse was brought into focus following relocation. Involving parents and young people as voices of experience within models of engagement has always felt like a natural approach to guide clinical care and research. Between 2004 and 2016, three studies and one European workshop were completed using a range of research or engagement methods; narrative enquiry, interpretive phenomenological analysis, ethnography, and intersectionality. Throughout this journey, engagement with families, youth, support groups and advocates has been a cornerstone in being able to work together looking at understanding (as best we can) the needs, hopes, and

challenges people face when living with rare conditions of sex development differences or intersex. Engagement is pivotal in thinking about change since we are reminded that research takes time to translate to practice. Being positioned within a space whereby all involved were part of the journey was a privilege. By facilitating conversations to inform research design, establishing advisory groups and youth and parents as researchers, directed how information could be shared "real time." Creativity often stemmed from participants, as they liberated their talents and found new degrees of confidence. The aim of this presentation is to consider engagement through a lens of collaboration, narrowing in on aspects of success as well as failure, and thinking "with time" as a concept of engagement in how we work together in future public engagement.

How Do We Engage and Listen to People's Perspectives on Everyday Lives, Future Hopes Across Countries and Social Groups?

Caroline Sanders, *Living with CAH Group*
Joanne Hall, *Living with CAH Group*
Arianne Dessens, *Erasmus Medical Center*
Faisal Ahmed, *Developmental Endocrinology Research Group*

Feeling connected often means providing opportunity for engagement in an effort to understand others' experiences. For individuals who experience a condition that affects sex development disharmony associated with health interventions, social discourse, inequity, and inequality exist. Despite a shift in care and dialogue, the knowledge and evidence surrounding interventions and outcome is varied. In such contexts, the voices that could help us to steer future research priorities can be marginalized. Our aim, as part of the COST Action BM1303 DSDnet supported by COST (European Cooperation in Science and Technology), was to engage with individuals or parents of children with these rare conditions as well as support groups to listen, learn, and ask: what now?

Consensus around a workshop engagement approach that gave the significant voice around health and experience and policy to participants (individuals and parents) was formulated with leadership from a support group lead. A variety of people attended the social network meeting and the facilitated workshop. People from nine different European Union countries attended. Professionals were positioned to be unobtrusive, to listen, and when invited ask questions. Respectful engagement allowed for a safe space to be created that allowed for open, honest, and at times difficult narratives to be shared and heard. Future research inquiry was explored, participants confidently questioned existing research streams, and raised awareness of areas that were still unknown or uncertain.

Overall, the workshop evaluated positively and the model can easily be repeated in other contexts and settings.

“Talking About Dying Is So Difficult”: Nurse Practitioner Students’ Reflections on End-of-Life Discussions

Craig R. Sellers, *University of Rochester School of Nursing*
Lynne Massaro, *University of Rochester School of Nursing*

Nurse practitioners (NPs) are increasingly called upon to have discussions about advanced care planning (ACP) with patients and their families in diverse health-care settings. ACP includes discussions as well as helping patients complete written documentation of their wishes for end-of-life (EOL) care. Health-care proxy or durable power of attorney for health-care forms and living wills are routine mechanisms for documenting these wishes. Documents such as the Medical/Physician Orders for Life-Sustaining Treatments are also used to document wishes for patients with serious illness who might die within a year. Three years ago, after revision of three NP specialty programs to meet national population and role objectives, our state education department approved the addition of new gerontology content to our primary care and acute care programs. One component of the gerontology curriculum focuses on ACP in accordance with the End-of-Life Nursing Education Consortium recommendations. In the final semester of the programs, students participate in a didactic module on ACP. As an assessment of learning for this module, students complete ACP documents for themselves, and then, taking on the NP role, they talk with and help one other person complete the forms. Students then complete a reflection paper describing their experience of ACP planning for themselves and another individual.

Using qualitative descriptive analysis, we describe how NP students learn to talk about advance care planning. Based on student reflections ($n = 50$), our findings suggest that students highly value this exercise as it helps increase their confidence in having future ACP discussions.

Male Involvement in Illness Recognition, Decision Making, and Care-Seeking for Maternal and Newborn Complications: A Qualitative Study in Jigawa State, Northern Nigeria

Vandana Sharma, *Abdul Latif Jameel Poverty Action Lab*
Nadège Giroux, *Paris School of Economics*
Jessica Leight, *Williams College*

Maternal and newborn mortality continue to be major challenges in Nigeria, especially in the north where levels are highest. We conducted 40 illness narratives between June and November 2015 to explore the process and sequence of symptom recognition, decision-making, and care-seeking among families experiencing maternal and neonatal illness and deaths in Jigawa State, Northern Nigeria. Given the central role that men play in Nigeria in household decision-making, 10 in-depth interviews were conducted with husbands to understand their knowledge and perceptions related to maternal and newborn complications as well as their

roles in birth. Men were aware of dangerous symptoms in pregnant woman and newborns as well as the high rate of maternal and neonatal mortality. However, the majority of men did not discuss symptoms with their wives and were not directly involved in the prenatal visits or the delivery processes, considering these a woman’s domain. Key differences in recognition of complications, decision making, and care-seeking patterns between maternal and newborn illness and death cases were also identified. Compared to the maternal cases, much less care-seeking was reported for newborns, especially in cases that ended in death. Husbands played the lead role in decision-making for maternal death and neonatal illness cases, while female relatives and traditional birth attendants led decision-making around Post-partum hospitalization (PPH), and mothers were the principal decision makers in neonatal deaths. We argue that interventions in this setting need to be more inclusive of males and other family members and take into account differences between maternal and newborn recognition and care-seeking.

“It’d Be Easier If She’d Died”: Researching and Reporting “Taboo” Issues

Pat Sikes, *University of Sheffield*
Mel Hall, *Manchester Metropolitan University*

In the UK context where the emphasis is (quite rightly) on living well with dementia, on positivity and enabling approaches, it can be difficult for researchers to investigate and report negative experiences of both those with dementia and of their family members. Failing to represent perceptions and experiences as they are lived, however, does a serious disservice to the research endeavor and can prevent policy and service development and positive change. This presentation draws on stories told by twenty-two, 6- to 30-year-old participants in an Alzheimer’s Society (UK) Funded project that took a narrative and auto/biographical approach to investigate the perceptions and experiences of children and young people who have a parent with young onset dementia. Sometimes the stories were not easy to hear, especially when they challenged dominant master narratives around dementia. When these stories were reported in the national media, there was some vociferous criticism. Having asked the young people to share how life was for them, the researchers felt ethically bound to respect and disseminate their accounts. Researching and representing “taboo” and sensitive topics and views raise a myriad of issues that will be explored here.

To Have a C-Section or Not: Understanding Planned C-Section Decision-Making Experiences of Migrant and Canadian-Born Women

Priatharsini (Tharsini) Sivananthajothy, *University of Alberta*
Zubia Mumtaz, *University of Alberta*

Caesarean sections (C-sections) can be lifesaving surgical interventions; however, they place women at higher risk of

immediate complications. C-section rates are higher in migrant women highlighting an area of concern. Current literature shows women to have highly contributed to elective C-section decisions, and therefore women may be playing a large role in planned C-section decisions. However, research specific to migrant women's experiences of planned C-sections remains limited. Given this, the present study aimed to explore how decisions to have planned C-sections are made within the experiences of migrant women and whether their experiences differ from that of Canadian-born women. A qualitative study using a focused ethnographic approach was conducted at a teaching hospital in Edmonton from March 2015 to January 2016. Women who had a higher risk of undergoing a C-section, both migrant women who immigrated to Canada after 2004 ($N = 36$) and Canadian-born women ($N = 18$), were included. Data were collected through observation of prenatal appointments and postpartum in-depth interviews. Written informed consent was obtained from all participants, and ethics approval was received from the University of Alberta. Our findings reveal women, both migrants and Canadian-born, were the primary decisions makers for most planned C-sections. While both groups' decisions were based on medical and experiential factors, social factors such as lack of family support had a larger effect on migrant women's decisions. Our findings suggest there is a need to address social factors, which affect migrant women and their maternal health experiences in order to reduce inequities.

Power and Knowledge: Understanding How Migrant Women and Canadian-Born Women Participate in Obstetrical Decision-Making

Priatharsini (Tharsini) Sivananthajothy, *University of Alberta School of Public Health*

Zubia Mumtaz, *University of Alberta School of Public Health*

Research in Canada shows migrant women to have higher rates of C-sections compared to Canadian-born women. Communication barriers including lack of ability to negotiate have been cited as potential contributing factors. However, the complexities of patient participation in decision-making have not been well explored in migrants, especially in the context of labor and delivery. The present study aims to understand migrant women's ability to make decisions during labor and delivery including C-section decisions and how they differ from the experiences of Canadian-born women. A focused ethnography was conducted at a hospital in Edmonton from March 2015 to January 2016. Migrant ($N = 36$) and Canadian-born women ($N = 18$) who had a higher risk of undergoing a C-section were included. Data were collected through observation of prenatal appointments, labor, and delivery and in-depth interviews. Written informed consent was obtained from participants, and ethics approval was

received from the University of Alberta. Participation experiences, including barriers faced, were found to be similar between both migrant and Canadian-born women. Power imbalances prevented both groups from participating in decision-making. These included authority of providers, lack of opportunity to participate, and limited sharing of information and communication barriers specific to migrant women. However, a group of migrant and Canadian-born women overcame these power imbalances due to privileged knowledge about patient rights and obstetrical interventions available. These findings suggest that participation differs due to the exclusivity of information on patient rights and care. These inequities may be based in socioeconomic class differences and need to be further explored.

Youth Substance Use and Harm Reduction Strategies: A Cross-Site Analysis of Three Communities

Allie Slemmon, *University of British Columbia*

Emily Jenkins, *University of British Columbia*

Rebecca Haines-Saah, *University of Calgary*

School and community approaches to youth substance use are predominantly informed by prevention- and abstinence-based frameworks, yet these approaches have been critiqued as unrelatable to youth and ineffective at reducing substance-related harms at the population level. Emergent harm reduction approaches to youth substance use have demonstrated efficacy in youth response and health outcomes, yet remain politically controversial and with a limited evidence base. Further, youth perspectives on harm reduction approaches to substance use are frequently absent from research and program development. Through the Researching Adolescent Distress and Resilience study, 83 qualitative interviews were conducted with young people across three communities—urban, suburban, and rural—in British Columbia, Canada. A cross-site analysis was undertaken to explore topics of substance use and harm reduction, a process which included identification of broad themes across the data, and subsequently subthemes within each site. Two themes were identified: youth context and experiences of use and strategies for substance use management. Within-site analysis demonstrated that youth developed and utilized ad hoc strategies for minimizing harms related to substance use that were situated in their geographical, socio-cultural, and community contexts. Utilizing a novel cross-sectional analytic approach contributed to the identification of the need for contextually-relevant harm reduction programming that is responsive to the lived realities of young people. The incorporation of youth perspectives on harm reduction is necessary for ensuring that substance use approaches avoid a one-size-fits-all model and are resonant with young people's experiences of substance use within their peer groups and communities.

Resident Experiences Living in Designated Supportive Living in Alberta: What Is Working Well and What Can Be Improved?

Sonja Smith, *Health Quality Council of Alberta*

A primary strategy of the Health Quality Council of Alberta (HQCA) is to monitor the health-care system over time and enable comparison where appropriate to inform improvement. In 2017, the HQCA piloted an interview project that engaged 32 designated supportive living (DSL) residents in in-depth interviews to explore in greater detail their experiences with living in supportive living. This pilot project ran complementary to the 2016 HQCA Supportive Living Resident Experience Survey that captured 2,870 DSL residents' general experiences living in supportive living across Alberta by questionnaire. The purpose of the interview pilot project was to explore, firsthand, what residents felt were areas for improvement, and what they felt was working well at their own facility. Residents were recruited in Calgary and surrounding area from 10 facilities that scored highest and lowest based on a rating from the 2016 survey which asked residents to rate their facility from 0 (*worst experience*) to 10 (*best experience*). Facilities selected included rural and urban facilities as well as large and small. The results of these interviews will be used to identify and report on drivers of excellence and areas for improvement to stakeholders including residents, their families, facility staff, Alberta Health Services, and owners and operators of supportive living facilities in Alberta. Residents' recommendations for improvement can be used to inform practice and continuing care policy in Alberta. In addition, the results of these interviews will inform the questions that are asked in future iterations of HQCA surveys.

Nursing Student Placement: Critically Examining Culturally Responsive Pedagogy

Oona St-Amant, *Ryerson University*

Nisha Sutherland, *Lakehead University*

In recent years, the effects of globalization and greater cultural diversity among nursing students and the communities they serve has placed significant demand on traditionally Eurocentric nursing education programs to better integrate culturally focused content into curricula. In response to this demand, many nursing programs in Canada have either integrated or endorsed student placements in the Global South or Canada's northern communities. Although there exists important research that examines the "study abroad" experience in fields such as social work and international development, the majority of this research focuses on traditional international locations, particularly in the Global South. Using critical ethnography, this research examines the culture that shape nursing student placements internationally and in Canada's northern communities at two sites. The specific objectives are to (1) clarify how global and local knowledge are integrated

alongside institutionalized knowledge in nursing curricula relevant to international and northern Canadian student placements; (2) identify what social processes shape the formation and negotiation of relationships among faculty, staff, students, and community partners, locally and abroad; (3) begin to clarify (a) what conditions support and strengthen the integration of local knowledge in nursing curricula and (b) what changes are needed in nursing education and program delivery to enhance the quality of student learning related to work with these communities. Although this research focuses specifically on the field of nursing, the results will be important to numerous fields such as education and social work, in which research focuses on student placements with Canada's northern communities remains sparse.

A Mixed-Methods Formative Evaluation Using Low-Income Adults' Experiences With a Smartphone-Based Nutrition Education Program

Sarah Stotz, *The University of Georgia*

Jung Sun Lee, *The University of Georgia*

Jori Hall, *The University of Georgia*

The purpose of this research is to conduct formative evaluation exploring participants' expectations and experience of an innovative smartphone-based eLearning nutrition education program, titled Food eTalk. Smartphone-based eLearning is a novel nutrition education program delivery method for low-income U.S. adults. We employed a constructivist, longitudinal, mixed-methods, case study approach including 16 focus groups (8 pre and 8 post with a total of 45 participants) and 54 individual interviews (with a total of 19 participants), self-reported demographic surveys, and website user tracking data. Participants ($N = 64$) were recruited using maximum variation purposeful sampling from rural and urban areas in a Southern U.S. state. All participants were interviewed before and after they had access to Food eTalk. Interviews were analyzed using a constant-comparison coding technique to construct themes. Descriptive statistics were employed for demographic and user tracking data. Lack of motivation to engage in Food eTalk emerged as a formidable barrier. To enhance motivation, participants recommended Food eTalk should include very short lessons featuring interactive games and videos, relevant content such as recipes and tips to feed "picky" children, and extrinsic incentives such as food coupons to mitigate barriers to healthfully eating and increase engagement. Additionally, participants found the smartphone-based format of Food eTalk easy to navigate and better designed than anticipated. These findings suggest voluntary nutrition education eLearning programs need to be formatted to mimic typical smartphone use, include content deemed relevant by the priority audience, consider external incentives to increase engagement, and emphasize solutions to barriers to healthful eating.

Re-Presentations of Life with Cancer: Difficulties of Containing Experience

Ulrich Teucher, *University of Saskatchewan*

Susan Gubar (2016) has noted that writing about life with cancer can perform therapeutic functions, reconstitutions of the self, and discoveries of multiple ways to live with the disease (pp. 2–5). In this article, I am tracing some cancer patients' multiple ways of representing life with cancer, whether through poetry, prose, art, and/or movies, as these patients encounter new developments in their illness, shifts in diagnoses, changes in therapies, metastases, new cancers, or cancer turning into chronic illness (e.g., Benedict 1989, 1993; Clifford 1996, 1998; Cousins 1979, 1989; Friebel 1994, 1996; Gubar 2012, 2016; Handler 1996, 2008; Harwell 1985, 1997; Hoek 1995, 1997; Lenker 1984, 1993; Lorde 1980, 1988; Lucas 2005, 2015; Sanders 1997, 1998; Servan-Schreiber 2007, 2011; Shapiro 1997, 2002; Wadler, 1992, 1997a, 1997b, 2005, 2013). Trying to give form, voice, and images to their experiences, artists' attempts at creating continuities invariably shift toward changes, for example, from gestures of power, attitude, and new appreciations of life, to more modest designs and disappointments (Lucas 2005, 2015), or from a master war narrative of positive attitudes and denial of death to changes ("yet again") strung together in a collection of short stories that embrace minutiae of daily life, for now (Handler 1996, 2008). These multiple retellings and representations may function as metaphors of the difficulties to contain experience when living with cancer.

In the Presence of Power: Social Context and Disclosure of Adverse Events by Medical Residents in Focus Groups

Kelly Thomson, *University of Toronto*
Maitreya Coffey, *University of Toronto*

Focus group methodologies have historically been viewed as adequate for "applied research" but of questionable value for scholarly studies (Barbour & Kitzinger, 1999; Hollander, 1997; Kitzinger, 1994). Positivist researchers saw focus groups as an efficient but likely biased way to solicit individuals' views while constructivist researchers saw focus groups as largely contrived situations that did not reflect "real" social groups. However, with increasing attention to postessentialist, performative views of identities and "realities" (Goffman, 1959; West & Zimmerman, 1987), scholars have begun to see carefully designed focus group studies as valuable opportunities to examine social interactions. This article revisits a mixed-method study of residents' knowledge, attitudes, and experiences about disclosure of adverse events (Coffey et al., 2010). In this article, we focus on an intensive analysis of how social context shaped the interaction among residents and how

they discussed adverse events. Focus groups were conducted with three groups of pediatric residents. In an attempt to explore potential differences at varying levels of training, three focus groups were arranged: one each for first-year (R1s) and second-year (R2s) residents and a combined group for third- and fourth-year (R3/4) residents. Due to a scheduling conflict, two of the R4s attended the R2 group instead of the third as had been planned. We illustrate how the discussion of adverse events in the homogenous groups unfolded in quite similar ways, while the discussion of adverse events among second-year residents appeared to be stifled by the presence of senior residents. We discuss the implications for interpreting research findings and the opportunities focus groups offer for gaining greater insight into how social context affects social interaction.

Precarious Lives: A Critical Examination of Homeless Youth Transitions to Independent Housing

Naomi Thulien, *University of Toronto*
Denise Gastaldo, *University of Toronto*
Elizabeth McCay, *Ryerson University*
Stephen Hwang, *University of Toronto*

There have been only a handful of longitudinal studies designed to examine the trajectories of youth who exit homelessness. Moreover, none of these longitudinal studies were designed to exclusively examine the experiences of youth transitioning to independent housing, where youth pay market rent and are required to be more self-sufficient. The goal of this study was to produce an emic perspective on the experiences of formerly homeless youth as they transitioned into independent housing and attempted to achieve meaningful social integration. The study was guided by a Post-colonial Feminist theoretical framework alongside the World Health Organization Commission on Social Determinants of Health conceptual framework. A critical ethnography was utilized to reveal socioeconomic and political factors that shape the transition to independent housing and meaningful social integration. During 10 months of fieldwork, the lead author met every other week with nine formerly homeless youth who had recently moved into independent housing. Three key findings emerged: (1) Youth appeared "successfully" housed but lived in chronic precarity, (2) youth experienced a shift in identity and employed this as a self-preservation strategy, and (3) the process of independently maintaining housing undermined the youths' sense of mastery and control. Despite their remarkable agency, participants' lack of tangible and intangible resources meant they were housed in poverty and remained marginalized. We propose a new conceptual framework, highlighting the tangible and intangible resources needed by youth attempting the daunting task of transitioning off the streets.

(M)Othering Within the Context of a Shelter: Prison and Refuge

Stephanie Tomicic, *University of Ottawa*

Denise Moreau, *University of Ottawa*

Wendy Peterson, *University of Ottawa*

Single mothers and their children are the fastest growing subsection of the homeless population in Canada. Emergency shelters provide a response for women and their children who are experiencing a housing crisis due to domestic violence, or other precipitating factors that result in them becoming homeless. It is important for public health providers, service providers, and policy makers to understand the lived experience of mothering in a shelter in order to design services that effectively support optimal health and social outcomes for homeless mothers and their children. The objectives of the study were to gain critical insight into and to understand how women living in shelters “mother” their children. Using van Manen’s interpretive phenomenological approach, semistructured interviews were conducted with 30 mothers living with their children in four shelters in a large urban center in Canada. The interviews were conducted in English, French, and with a cultural interpreter. Preliminary findings show that mothers and their children struggle while living in a shelter and that many mothers continue to suffer abuse through postseparation violence. What’s All The Hype Around SPOR: Haven’t Qualitative Researchers Always Engaged?

Virginia Vandall-Walker, *Patient Engagement Platform, AbSPORU*

It is well recognized that engaging patients and their families in health delivery decisions is key to providing good care. This impetus has recently spread to the inclusion of the patient voice in health research, with the focus shifted from participation as subjects, to engagement as partners across the various phases of health research. Following the 2011 release of the Canadian Strategy for Patient Oriented Research (SPOR) by the Canadian government through the Canadian Institute for Health Research (CIHR), a number of cross-Canada research networks and provincial support centers called SPOR Support for People and Patient-Oriented Research and Trials (SUPPORT) Units have been developed to provide the resources and supports necessary to build and sustain patient-oriented research across the country. Alberta was the first province in Canada to launch a SPOR SUPPORT Unit, comprised of seven platforms including a Patient Engagement (PE) platform, to promote the “meaningful” engagement of patients and researchers in the conceptualization, design, execution, and translation of health research as well as in governance related to research initiatives and evaluation of PE in research. In this presentation, the spectrum of patient and researcher engagement in health research, developed with stakeholder input, is introduced. Real-world examples and lessons learned are discussed from both the researcher and patient perspectives. Challenges and benefits to engaging together in health research are explored and the imperative to evaluate PE activities in health research is emphasized.

Mindfulness as a Tool for Reflexivity in Narrative Research

Pamela van der Riet, *University of Newcastle*

This conference presentation will argue for mindfulness as a tool for reflexivity and role in narrative research. Reflexivity is an important strategy to ensure trustworthiness and rigor of qualitative research. Through a process of reflexivity, we can gain awareness of own assumptions in our own writing that may well shape our research encounters and analysis. It has been pointed out that researchers should subject themselves to the same level of scrutiny that they direct toward their participants. Qualitative researchers need to look at what frames the way we see things and probe our own embodied responses. As narrative inquiry researchers we live in the midst of our participants’ stories. We have an ethical responsibility to our participants to be mindful of how we coconstruct the narratives of our participants. Narrative inquiry is a relational and interpretive methodology with the researcher situating themselves in a relational way with their participants; often dancing in an out of involvement and coconstructing stories with participants. Mindfulness is an engagement in the present moment in a nonjudgmental way. Essentially, it is remembering to pay attention with care to our research encounters. There is emerging evidence that mindfulness meditation can cause neuroplastic changes in the structure and function of the brain so regulating attention emotion and self-awareness. The science of mindfulness will be explored in this presentation along with the benefits. Furthermore, there will be a short exercise on mindfulness to engage participants to be responsible and reflexive narrative researchers.

On the Meaning of Premature Infants’ Behavior

Michael van Manen, *University of Alberta*

As she examines Jon, his eyes open, casting darted looks. His body moves in sharp, wriggling twists. With each palpation of his abdomen he turns more flushed, arching his back. His breathing pauses momentarily only to quicken and then pause again. And as the exam continues, his face darkens in redness. His body and limbs become limp. Breathing pauses, and his eyes close. Redness becomes cyanosis as heart rate and saturations fall. What is expressed in the behavior of premature infants whose bodies arch, extremities shudder, and breathing pauses in response to stimulation? Drawing on behavioral observations of extremely premature infants admitted to neonatal intensive care, this study explores the phenomenon of disorganized behavior as described in the Synactive Theory of Development, the theoretical basis of the internationally recognized Newborn Developmental Care and Assessment Program. While we do not know whether, how, or what it is that these infants are actually experiencing, if we observe their behaviors

pathically we may tentatively grasp their inceptual meanings. For the behavioral conceptualization of disorganized behavior, we may question whether there is order to the disorder as lacking contact, unsettling stimulation, and exposed bodiliness. Although we need to be careful that we do not submit to intersubjective sensitivities that are rooted in faulty empathic presumptions, from pathically wondering about the experiential life of premature infants, we may find care in compassion and understanding.

The Creation of Program Evaluations for a Peer-to-Peer Mentorship Program: Challenges and Lessons Learned

Nicole Bownes, *University of Alberta*

Rhea Van Raay, *University of Alberta*

Natasha Wilson, *University of Alberta*

Evaluation is an essential component of any program to document progress, refine current practice, promote continuous development, and ensure the program is addressing its objectives. Using qualitative methods to do so is of particular use, as it allows for the description and analysis of specific experiences and more in-depth explanation of various program aspects. Program evaluation may be considered a method for engaging participants in research. With these considerations in mind, Mentor Us, a peer-to-peer mentorship program for graduate nursing students, has focused on developing and implementing program evaluations to determine and enhance program quality while increasing participation. As codirectors of the program, we hope to share some of our challenges and lessons learned over the past year with planning, developing, and implementing program evaluations. More specifically, we will share our experience engaging outside guidance and participation in the development stages, the process and reasoning for creating targeted evaluations for mentors, mentees, and nonmembers as well as the methods of dissemination to ensure sufficient response rates. Future directions, including the introduction of focus groups, will be considered. We hope to provide a unique perspective on some of the more commonly experienced issues in program evaluation.

Children's Perceptions About Leaving Home: Accompanying Their Mothers to Domestic Violence Shelters

Anat Vass, *The Hebrew University of Jerusalem*

This study examines children's perceptions about leaving home, accompanying their mothers to domestic violence shelters. Abused mothers and their school-aged children who recently leaved domestic violence emergency shelters were assessed by individual interview. Interviews with 32 children between 8 and 12 years of age were analyzed using a thematic analysis method. As part of a larger qualitative study, a purposive sample of children that had been residing in four domestic

violence emergency shelters in Israel was interviewed about witnessing intimate partner violence before leaving home. Three main themes were identified: How children talked about abuse of their mother, described their own perceptions of violence, how children articulated the moment they had to leave home with their mothers, and how children acted at the moment they realized they had to leave and go to shelter. The findings of this research support the idea that children's perceptions and interpretations are important enough to understand, and it has clinical implication about intervention needed for those children. Findings are also important for further research in other issues that are missing in literature and are relevant to extent our knowledge of this topic issue.

Health and Legal Literacy for Migrants: Social Justice and the Human Right to Health Care

Bilkis Vissandjée, *Université de Montréal*

Wendy E. Short, *Queen's University*

Karine Bates, *Université de Montréal*

Based on a critical analysis of literature, an overview of the challenges associated with delivering on the right to access quality health care for international migrants to industrialized countries will be provided. One of the questions refers to which group of professionals is best equipped to provide health and legal literacy services. Both rights and challenges are approached from a social justice perspective with the aim of identifying opportunities to promote greater health equity—that is, to go beyond the legal dictates enshrined in principles of equality, and target as an ethical imperative a situation where all migrants receive the assistance toward equitable access to health care. Viewing the topic from this perspective makes evident a gap in both research literature and policy. The narrative review identified that while health literacy is debated and enshrined as a policy objective, and consideration is given to improving legal literacy as a means of challenging social injustice in developing nations, no discussion has been identified that considers assisting migrants to gain legal literacy as a step toward achieving health literacy in lieu of improved health outcomes as well as leading to critical participation as members of their adoptive society. Increasing migrant health literacy, amalgamated with legal literacy, aids migrants to better access their human right to appropriate care, which in turn demonstrably assists in increasing social engagement, citizenship, and productivity. A debate is required to determine who is best placed to provide health and legal literacy services and how they should be resourced, trained, and equipped.

Clinical Encounters in the Context of End-of-Life Care: The Ethics of Communication

Bilkis Vissandjée, *Université de Montréal*

Patrick Durivage, *CIUSSS Centre Ouest de l'île de Montréal*

Isabelle Van Pevenage, *CIUSSS Centre Ouest de l'île de Montréal*

In Canada, as in most Western countries with significant rates of immigration, the proportion of people who are unable to

adequately speak the local dominant language while interacting with services outside the home has increased tremendously over the past 70 years. Language is central toward understanding one's needs, especially those which may be tightly ingrained with a woman or man's personal identity. Language is also known to be the basic means through which emotions, complex thoughts, beliefs, and values are experienced and expressed. In a clinical context, language is a primary medium for providing quality care, while attending to ethical considerations such as ensuring the establishment of a trusting relationship so that consent for specific procedures is adequately obtained and that patient dignity is respected. Over the past few years, language barriers have been determined to be a prime obstacle to accessing and receiving adequate health-care services. Such barriers, particularly in regard to primary and preventive care, have been associated with stressful situations for both users and caregivers and increased overall cost of care as illustrated by increased use of higher intensity services and inefficient clinical encounters. The latter have been associated to an increased risk of excessive and unnecessary interventions as well as an increased probability of clinical error. Greater risk of misdiagnosis, suboptimal pain management, and less effective management of chronic diseases such as diabetes and asthma have been reported. It has also been demonstrated that lower patient satisfaction in the presence of linguistic barriers leads to lower adherence to treatment, as health-care professionals may be less likely to do teaching or discuss preventive measures. Effective communication is therefore central to the provision of compassionate, high-quality nursing care. In this backdrop, in Canada, an increasing number of women and men are achieving their wish to die in the familiar surroundings of their own homes, which means that providing high-quality, person-centered end-of-life care is likely to be an important part of the primary health care. Care at the end of life may present a number of trust building, legal, and ethical challenges within primary care practice. Given that language is a special vehicle for attending to ethical clinical norms such as informed consent, dignity, and respect, this presentation aims (1) to discuss the opportunity for an ethical primary care practice to consider selected challenges at the end of life and (2) to highlight the challenges in providing care in the context of end-of-life care with a conscious and sensitive approach to effective communication.

Maternity 2.0: Participation in Social Media and Informational Habitus

Maryline Vivion, *Laval University*

Maternity is influenced by many normative representations that are culturally specific. For many well-educated, wealthy parents in North America, children's needs are central and mothers' involvement and dedication are perceived as essential for their children's development. These norms and ideals pressure new mothers who need to make several decisions for the health of their children. In this normative context, where knowledge is

valued and crucial for "informed" decision-making, the Internet appears to be an unavoidable source of information for mothers. On social media websites, many parenting groups portray themselves as being essential resources to help mothers fulfill maternity requirements. Therefore, it is important to understand how the content seen on the Internet shapes mothers' attitudes and health decisions for their children. This communication is based on my PhD project that aims to explore the influence of mothers' participation in social media groups in the way they provide care to their children. The findings are based on an online ethnography which was carried out in 2015 on two social media groups for mothers. Nonparticipant and participant observations were conducted as well as 19 individual interviews with mothers. In this presentation, based on Bourdieu's concept of habitus, I will explore how information on the Internet has modified the informational habitus of mothers, especially through the emergence of "virtual communities." I will demonstrate how mothers articulate the concept of informational habitus around three notions: their practices to get informed, the way they assess information credibility, and their reflexivity toward the information they consult.

The Female Aging Body (FAB) Project: Understanding Perspectives on Health, Body Image, and the Aging Body to Inform Healthy Aging Policy

Pamela Ward, *Centre for Nursing Studies*

Sue Ann Mandville-Anstey, *Centre for Nursing Studies*

Erin Cameron, *Memorial University of Newfoundland*

Alyssa Coombs, *Memorial University of Newfoundland*

There is a growing body of literature that focuses on how societal ideals of health and beauty are impacting health behaviors. The body has become the focus of much attention in recent years with many critical researchers suggesting that dominant discourses of health and beauty are driving negative health behaviors and promoting unrealistic body norms. While much of the body image literature has focused on children and young adults, less research has focused on older populations, despite evidence that only 12% of older women are satisfied with their body size (Runfola et al., 2013). In this presentation, we will provide an overview of the Female Aging Body Project, a two-phase poststructural feminist study designed to explore the impact of dominant health discourses in the lives of aging women. The intent is to better understand how the biomedical paradigm serves to shape views of the body and the utilization of health-care services and health promoting behaviors. We will report results from phase one which included focus groups and interviews with women over 60 years of age. We will also provide a discussion of phase two which consists of an interactive body image workshop that includes an educational component, an adapted physical activity, a body mapping activity, and media literacy discussions. We will highlight how this research is not only helping to

inform aging-centered initiatives in Newfoundland and Labrador, but also how this work can function to inform health policy and practices related to aging populations on a broader scale.

Rapid Review and Synthesis of Qualitative Evidence: A Search and Mapping Review of Existing Guidance and Examples

Laura Weeks, *University of Sheffield*
 Fiona Campbell, *University of Sheffield*
 Laura Weeks, *CADTH*
 Andrew Booth, *University of Sheffield*
 Andrea Smith, *CADTH*

Data from the Cochrane Qualitative and Implementation Methods Group register confirm that qualitative evidence syntheses are proliferating. Rapid qualitative evidence syntheses are likewise increasing due to an apparent policy imperative for person-centered health care and to ensure that patients' and caregivers' perspectives and experiences are central to health-care decisions. The need for rapidity requires either a substantial increase in resources or, more commonly, a compromise in rigor. Generic methods are developing for many types of rapid review, but we are not aware of published guidance for rapid qualitative evidence synthesis. In order to inform de novo guidance, we are conducting a systematic mapping review to identify existing guidance and published examples. We have searched Medline and CINAHL using medical subject headings and keywords related to "rapid reviews" and "qualitative" research and screened the 1,771 resultant citations independently in duplicate to identify relevant papers. We will summarize methodological papers and related guidance using a Search, Appraisal, Synthesis, Analysis framework. We will summarize approaches used to abbreviate the synthesis process by authors of published examples. Our analysis and interpretation will focus on the implications of abbreviating various steps of the synthesis process. Overall, our review will identify the extent to which current guidance and practice offers a methodological evidence base to develop common expectations and methods for rapid qualitative evidence synthesis.

Sequential Simulation Model Development

Sharon Marie Weldon, *Imperial College London*

Sequential simulation (SqS) is a physical form of simulation that recreates care pathway trajectories rather than single episodes of care. Current physical simulation in health care focuses on specific tasks or particular teams and settings. However, the patient perspective is a journey through the care system and not an isolated component. To date, SqS has been used for a range of applications, including training multidisciplinary teams on end-of-life care, developing integrated care approaches, quality improvement projects, designing new models of care, evaluating new interventions, and improving care of the deteriorating patient in an acute setting,

to name but a few. Many applications are possible, and therefore the design process can be lengthy and complex. This article outlines an approach the author took over a 3-year period to generate a usable SqS model through empirical and theoretical data. The model draws on process, observational, survey, and evaluative data to generate an understanding of the key components that constitute the design process of an SqS. This approach resulted in an empirically and theoretically driven model that can be used and refined by others in the field of health-care simulation.

Using a Variety of Research Methods and Angles to Understand a New Approach That Explores Health-Care Services

Sharon Marie Weldon, *University of Greenwich*
 Miranda Kronfli, *Imperial College London*
 Fernando Bello, *Imperial College London*
 Roger Kneebone, *Imperial College London*

Simulation is traditionally used for health-care professional training and assessment; however, its remit is much wider and new studies are emerging that highlight the breadth of opportunities it affords. We used simulation to engage professionals and patients in National Health Service (NHS) maternity services across a London borough. Six services were identified due to recognized disparities in care.

A form of simulation termed Sequential Simulation was used to recreate an expectant mother's 9-month care pathway, in order to engage staff and patients across sites in discussing strengths and challenges of their services. Due to this innovative approach to sharing learning in maternity care, several areas of research interest were identified. These included the engagement of health-care professionals and patients, the design of the simulation pathway, the perceived benefit of the simulation approach, the discussions generated in relation to the objectives of the project, the project process, sociocultural insights, and the educational opportunities that emerged. A range of methods and theories were used to investigate each angle including the mixing of methods where appropriate. This article discusses the array of research approaches used to understand this innovative form of engagement and quality improvement and generates a holistic understanding of sequential simulation's use in this setting. It argues the importance of a broad conceptualization when researching a complex intervention and illustrates how this can illuminate a complex area to best ensure benefit to others working in the field.

Traversing (Dangerous) Narrative Terrain: Dialoguing With Stories of Mindfulness in Palliative Care Nursing

Lacie White, *University of Ottawa*

Nursing is relationally embodied and morally situated, where compassionately engaging with people through suffering,

existential distress, and disease is central. Navigating this shifting and uncertain terrain is complex, particularly when caring for people who are dying and their families. To further understanding of how nurses can cultivate capacities to skillfully care for themselves and others in their practice, methodological approaches in nursing that can undertake these complexities are needed. In qualitative health research, and specifically within narrative research, many analytic approaches treat stories as inert objects, dissecting them into parts; rendering socially and culturally embedded layers within them invisible. As a result, (con)texts and evocative tones and textures are silenced, leading to disembodied reports. In this presentation, I will discuss using dialogical narrative analysis, grounded in the work of sociologist Arthur Frank, to understand the relationally situated texts and voices of nine palliative care nurses who offered evocative storied experiences of being mindfully present (or not) in the midst of “chaotic,” “shocking,” and “surprising” moments with people at end of life. As stories beget stories, rather than thinking solely about stories as objects, I will reflect on the process of thinking, feeling, listening, and writing with stories, following them into spaces yet known. Challenges of traversing terrain where stories converged and diverged, and were “good,” “dangerous,” and sometimes both simultaneously, will be shared. Finally, the value of representing stories in research reports will be emphasized as a way to stimulate response and generate dialogue within palliative care nursing communities.

Interprofessional Team Working and Person-Centered Care: How Can these Approaches Facilitate Patient Engagement in Care, Research, and Wider Social Discourse?

Erin Wilson, *UNBC*

Caroline Sanders, *UNBC*

Interprofessional (IP) team working and the concept of patient- or family-centered care are not new phenomena within the health and social care geography. How IP working transpires within primary care as well as secondary and tertiary settings to inform public engagement is critical as we shift toward a change of research priorities as considered in collaboration with public citizens. This presentation will bring together two different experiences of exploring IP teams across primary and secondary care from a region in Western Canada and a region in the Northwest UK. In reflecting on our experiences, we describe confluences as well as areas of divergence to examine potential trajectories that engagement may take over the coming decade. The reciprocal relationships that practitioners enact with patients occur in various spaces and places and influences opportunities for patient engagement. Yet, IP teams may be grounded in language or practices that are inaccessible to patients in role of expert patient or activist parent. Consideration of approaches that may foster meaningful public engagement deserve further attention. Current discourse of public engagement and leadership roles in IP teams is in transition.

Qualitative approaches may be well suited to examine what this means against a backdrop of social construction, funding models, and the need to liberate the talents of those we engage with.

Older Adults' Health Information Wants and Information Provided for Cataract Surgery

Herlinda Zamora, *University of Texas Health at San Antonio*

Health-care systems worldwide are experiencing a historic change as people are living longer. Older adults tend to have unique and greater health information needs and wants than younger adults. Meeting the health information needs and wants of older adults is at the crux of the informed consent process, such as when they are asked to provide consent for surgery. Guided by the Health Information Wants (HIWs) framework, this qualitative descriptive study explored the pre- and postoperative HIWs and information provided for cataract surgery. Data collection consisted of one-on-one interviews conducted with 15 older adult participants. The older adults described their individual perspective regarding health information wanted and information provided before and after cataract surgery. Data were transcribed verbatim, analyzed, categorized, and themes were identified using an inductive approach. The following themes were identified: What information I wanted, what information was provided, and perceived discrepancy between information wanted and information provided. The findings suggested that the health information needs and HIWs of older adults are critical elements of the informed consent process and that older adults' perspectives and voices are important to meet their unique health information needs and wants the interprofessional health-care workforce can use the insights and knowledge provided by this research to meet the individual health information needs and wants of older adults before and after surgery, thus moving forward in engaging patients and promoting a patient-centered informed consent process.

Spiritual Prosperity in Chinese Women With Breast Cancer: A Grounded Theory Approach

Jianxia Zhai, *Monash University Melbourne*

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The aim of this research was to explore the experience of posttraumatic growth (PTG) in Chinese women with breast cancer. Constructivist grounded theory methodology was utilized to understand Chinese women's PTG experience. Chinese women ($n = 24$) with breast cancer were recruited from a public, tertiary hospital in Shanghai, China. Data were collected via semistructured, audiotaped interviews from December 2016 to April 2017. Purposive sampling was used at the beginning of data collection and then guided by theoretical sampling. Memo writings were undertaken throughout the whole research process. One preliminary category has been

identified as spiritual prosperity. This category is composed of new priorities, appreciation of life, enhanced altruism, and closeness to ultimate power. The findings are suggesting that the spiritual prosperity is manifested in Chinese women with breast cancer. Due consideration needs to be given to the importance

of spiritual strength among Chinese women when adjusting to their breast cancer. There is also a necessity of considering Eastern spirituality such as being more altruistic and self-transcendent when designing supportive interventions to promote PTG in multicultural clinical settings.