

## Abstracts, Oral Presentations

*Listed alphabetically by title*

### **A Burden and a Blessing: Pediatricians' Perspectives on Working with Childhood Cancer Survivors**

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The return to the community after cancer treatment has been described by childhood cancer survivors and their families as a time of crisis, with psychosocial issues and feelings of being abandoned by the health care and social support system as one of the main concerns. As the literature documents, primary care physicians play an active role in the care of these pediatric cancer survivors during the post-treatment phase. However information is scarce on how these physicians deal with these patients' specific psychosocial needs or if they are even aware of them. What we do know is that cancer treatment completion has been identified as a psychosocially complex time for these children as they transition from the role of patient to survivor.

An exploratory qualitative research was conducted to gather the knowledge and attitudes of primary care physicians regarding the psychosocial health care needs of these children and their families after treatment completion. In-depth interviews with 12 primary care pediatricians that provide care to survivors in their communities were conducted. Analysis of narratives followed an inductive thematic approach. As part of our analysis four themes emerged: the pediatricians work: a journey full of challenges, barriers in the delivery of follow-up care to survivors and their families, economic factors: two standards of health, and communication as a central axis. Information obtained from this study constitutes a potential source for research initiatives, as well as for intervention and internship activities tailored to clinicians and health related graduate programs.

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### **A Graphic Method as Support for Self Narrative in a Context of Equivocal Clinical Diagnosis**

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In the realm of health, qualitative research's advantage over quantitative approaches mainly lies in its aptitude to elicit the patient's point of view regarding the clinical process initiated by his demand for care. Some health problems don't match with established aetiologies and, inversely, diagnostic categories might meet difficulties fitting with multifactor health problems. This type of situation is particularly true in cognitive disorders associated with ageing where there is no explicit sign to distinguish illness from aging process.

The method we propose is based on patients and relatives' narrative about an experience in memory clinic. A graphic chart drawn by our respondents offers at once a recapitulation of the qualitative interview made in first hand, adding the subject's self projection for his future to the narration. The departure point to arouse the narrative being the diagnosis announcement, the drawing adds more than just repeating the patient's memory problems. It depicts very schematically a life trajectory starting at the point chosen by the respondent as the one when frailty tints his life, and extends the narrative in an imagined future where illness and ageing are incorporated along with social relationships with his relatives. Graphic support are proposed as an interpretation tool available for clinicians interested in knowing how their expertise is metabolised by their patients and what effect it has on their patients' self positioning regarding the illness perspective.

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### **A Picture is Worth a Thousand Words: Using Concept Maps to Support Understanding and Dialogue of Self-Management Learning within a Recovery-Based Framework**

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Providers' understanding of how clients experience learning to manage a health condition is essential. Knowledge translation (KT) refers to how clients acquire knowledge upon which to base their decisions. This project represents an exploration of the KT process using concept maps as a KT product. Initially, 31 outpatients from five mental health programs partnered with student occupational therapists to create each client's visual map of their self-management learning journey including: key events, healthcare delivery experiences, messages taken away, and recommendations. Maps placed the client in the centre of their care where they could assume the liberating role of teacher, as well as reflective student on their quest to better manage the more debilitating aspects of the illness. Acting on their suggestions, a study was subsequently designed to support others learning from clients' knowledge and evaluate the maps as a communication tool. Clients met in focus groups to review maps, complete self-reflection questionnaires and discuss the maps' uses. Their recommendations were forwarded to

provider focus groups. Client and provider reviewers reported that although each map was unique and personal, they powerfully sparked reflection and facilitated learning about themselves and others. Providers, including Peer Specialists, continue to use the maps in practice as a basis for dialogue, collaborative planning and grounding services in clients' daily realities. Although the full extent of a map's impact cannot be captured, clients relayed how a chance encounter or comment significantly impacted learning self-management. This suggests that an encounter with a map can have as profound an effect.

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### **A Toolbox of Innovative Methods for Single Interviews with Disabled Children**

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*University of Toronto*

This presentation will describe innovative techniques, strategies and methods for engaging disabled children in a single qualitative interview. Literature on child qualitative methods most often describes study designs involving multiple interviews or prolonged engagement with children in participatory ethnographic designs. Little information is available regarding optimizing single interview data collection and almost none is focused on engaging disabled children in research. Yet, researching disabled children's experiences is vital to informing understandings of the impact of rehabilitation services on the lives of disabled people. We will address these gaps, drawing from a critically-oriented pilot study where we explored the beliefs, assumptions and experiences of children with cerebral palsy and their parents regarding the importance of walking. Following an overview of the study context and a brief outline of principles guiding critical children's research, we will discuss and illustrate three key aspects of our methodological approach: collaboration with parents; a toolkit of customizable interview techniques; and strategies to consider the power differential inherent in child-researcher interactions. Each of the methods in the toolkit will be described including: (a) warm-up activities, (b) role-play with puppets, (c) vignettes about an imaginary child who has cerebral palsy, (d) cartoon captioning, (e) photographs depicting children's geographies, and (f) sentence starters. Examples from our research will be used to illustrate what worked well and what was less successful. We will conclude with recommendations for interviewing disabled children that we suggest might be equally useful for interviewing individuals of varying age and abilities.

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### **A Visual Analysis of Canadian Medical School Websites as Promotional Tools and Representations of Social Positioning On Diversity and Equity**

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Institutional websites are forms of new media in the public sphere, through which representations of race and ethnicity, age, gender and disability are contested. Using a visual research methodology, I examine how the concept of diversity is or is not represented in the institutional discourses on the admissions website of Canadian medical schools. The data consists of images on the medical admissions websites of these institutions captured from October to December of 2010. Using a visual methodology adapted from (Chrisman, 2008; Rose, 2001 and Grady 2008), this paper focuses on three elements; image composition, context of production and historical horizon, to analyze the photographic images on these websites.

Analysis identified patterns of representation that may engender certain implicit or explicit beliefs about who may or may not be invited to apply for admission to medical school. Analysis suggests that minority groups and mature students tended to be underrepresented in Quebec when compared with medical schools in other provinces. This non--recognition or misrecognition reflects existing discourses on diversity within the medical profession and may ultimately have implications for the composition of medical school classrooms across Canada. This paper highlights how a qualitative visual methodology can reveal dominant discourses and institutional ideological orientations about diversity and equity.

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### **Adaptation of the Action-Project Method for Individual Interviews to Examine Secretive Eating Issues and Disorders**

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Contextual action theory (CAT) proposes that human actions are goal-oriented, socially constructed, and best understood in the context of everyday life experiences. As the primary research method stemming from this paradigm, Young and colleagues' (2005) action-project method (APM) involves examination of complex social phenomena through the description of the behavioral, cognitive, emotional, and social processes that pairs or groups of individuals take to achieve their goals. Within this theory, secret keeping can be conceptualized as a covert action that is socially constructed between the secret keeper and potential social supports. As such, CAT provides an innovative framework from which to examine secret keeping in the context of eating disorders and issues. However, doing so requires modification of standard APM procedures to account for the nature of secrecy and the action of keeping secrets. This presentation discusses how the phenomenon of secret keeping in the context of eating disorders/issues can be framed from a CAT perspective, and provides the rationale for, and potentiality of adapting the APM in a way that remains consistent with the central tenets of CAT. Additionally, a specific set of procedures for using APM to examine secrecy will be outlined, and specific examples of its implementation in a study of secret keeping in the context of eating disorders/issues will be provided.

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## **Aging and the Iranian Diaspora: A Narrative Inquiry of Life of Iranian Elderly Immigrants in Canada**

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Background: Canada is growing older and elderly immigrant population is growing even faster. Although immigrants make up almost half of the Toronto population, there is limited understanding of how to promote the quality of life of elderly immigrants. Iranian seniors immigrate to Canada individually through the immigration or refugee process, or through the sponsorship program. As many studies have shown immigration is a stressful process, especially when the complexity of aging is added. The purpose of this study was to explore challenges and barriers experienced by elderly Iranian immigrants living in Canada.

Method: Narrative inquiry provides an opportunity for researchers to listen to the first-hand life experiences of people and enable them to create effective services and programs or adjust services to meet immigrants' needs. Using Narrative inquiry method, I conducted 10 in depth semi-structured individual interviews and five focus group interviews. Participants were Iranian immigrant men and women aged 65 years or older.

Findings: Eight primary themes emerged from the study as follows: language barrier; financial limitation; lack of enough control over important aspects of their life; lack of independency; suffering in silence; fear of disclosure; lack of reliable, effective and appropriate support and services; and unpromising future.

Conclusion: Elderly Iranian immigrants, like many other immigrants, experience some degree of loss and disassociation after being dislocated. These experiences have affected their health, mental health, and general well-being. Listening to their stories can provide an opportunity for Canadian institutions to create programs tailored to the senior immigrants' needs. This study has implications for research, service delivery, and policy-making in addressing structural and cultural issues of elderly immigrants.

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## **An Exploration of How Spiritual Nursing Care is Applied in Clinical Nursing Practice**

Lydia Monareng

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Spiritual nursing care is a significant concept for nurses and form part of holistic care to patients. Many nurses do not understand the term and have difficulty integrating it into practice and consequently neglect this aspect of care.

The purpose of this study was to explore and describe how professional nurses provide spiritual care.

A qualitative, explorative and descriptive study, using Grounded Theory and Symbolic Interactionism was conducted. The population comprised of professional nurses from a public hospital in South Africa. Participants were recruited through purposive and snowball sampling. Observation, and individual and focus group interviews were used to collect data and observation. Data analysis were conducted with the assistance of and the NUD\*IST computer program, using coding, constant comparison methods and Tech's guidelines on data analysis.

Findings revealed that nurses struggled to conceptualise spiritual nursing care and to differentiate between emotional, social or psychological care. However, prayer with or for patients was seen as the most important and effective intervention mode.

Recommendations suggest that the scope of practice and nursing curriculum in South Africa be reviewed to ensure the inclusion of training to deliver spiritual nursing care. Spiritual nursing care is still a neglected component of patient care. The scientific worldview practices, beliefs and insufficient statutory endorsement of spiritual care hinder its realization in practice.

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### **An Exploratory Study of the Impact of a Group Self-Management Support Program: Listening to the Patient to Shape the Right Questions**

Sharon Johnston

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As self-management support programs for people with chronic diseases expand, it is vital to understand their impact on health attitudes and behaviours across diverse communities. This mixed methods study used four focus groups, one year after the intervention, to study participants' reactions and perceived impacts of attending the Stanford Chronic Disease Self-Management program (CDSMP) in one Ontario health region including rural and urban communities. A pilot survey on the type and frequency of community and health resources used for their self-management was also conducted. Common themes were identified through immersion crystallization analysis of focus group transcripts and data triangulation with survey results. Qualitative results revealed participants perceived diverse effects of the workshop. A change in physical activity patterns, improved sense of social connection, and better coping skills were some common themes. Barriers to self-management were experienced by almost all participants especially problems with the health system and patient-physician interaction. Increased use of several community resources, including those related to nutrition, was reported. Most of the dominant qualitative findings, including changed nature of interaction with friends and family as well as type of physical activity, would not be easily captured on a quantitative survey of behaviour change.

Self-management support is a complex and patient-centred concept. A qualitative research approach can help shape our larger scale evaluations to ask better questions. This will be essential as these

interventions move into different target populations and communities, in order to ensure the optimal investment of resources by participants and program implementers.

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### **An Occupational Therapist's Experience of Using Van Manen's Phenomenology Approach**

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This presentation offers the story and reflections of an occupational therapist adopting van Manen's approach. Therapists need an understanding of clients' experiences learning self-management of health conditions within the contexts of everyday living, and the unique and shared meanings these experiences can hold. As therapist-researcher, I was looking for a phenomenological approach that would build on my life experiences and perspectives to explore what it means to learn self-management with serious mental illness within the person's recovery journey and sociopolitical context. Van Manen's focus, use of both descriptive and interpretive elements and positioning the researcher as embedded in the interpretive process met my needs. Occupational therapists view people as engaging in the world as occupational beings; learning about ourselves and the world through participation in daily occupations as we shape and are shaped by our occupations and given environments. The approach was thoughtfully integrated into each study decision point. To examine embodiment through an occupational therapist lens, I added to van Manen's existentials 'lived occupation'. The praxis process of sensemaking was operationalized to my context. Strategies were used to benefit from language, writing processes and computer software during data transformation. Steps were taken to ensure rigor regarding balancing the participants' and researcher's voices, demonstrating transparency, retaining the complexities and the whole of participants' lifeworlds, while evoking meaningful connections and a life of its own with audiences. Reflections are offered concerning: "In the end, what did this approach bring and not bring to my study and was there added value?"

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### **Analysis Folios as a Tool For Teaching Qualitative Data Analysis**

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Christopher Fox

*La Trobe University*

Teaching undergraduate and graduate students how to do qualitative data analysis is no easy task. Often overwhelmed by the range of different methodologies, data collection strategies and approaches to analysis many students struggle with the theory and practice of data analysis. Exposing students to a range of different techniques for analysing qualitative data is difficult in many semester long courses however aptitude for qualitative analysis is increasingly being expected in many health and social research degrees. Drawing on experiences of teaching qualitative data analysis across two different university settings and courses this paper highlights how the use of data analysis folios can provide students with an opportunity to explore the different approaches and broaden their skill base. Some examples of course design and student work will be presented to illustrate how educators can use folios to provide opportunities for students to trial a range of data analysis techniques.

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### **Attentive Surveillance: A Intersectional Feminist Grounded Theory of Women Mothering through Intimate Partner Violence (IPV)**

Kelly Bentley

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Theoretical perspectives that inform mothering research are inadequate, guided by assumptions about mother-child relationships and portray women mothering through Intimate Partner Violence (IPV) in a negative light and as deficient. Further, existing theoretical perspectives largely ignore the contextual complexity of the family, their social environment, and women's capacities in caring for their children. We have little knowledge of mothering that is grounded in mothers' actions and accounts of mothering in the context of IPV.

An intersectional feminist grounded theory approach which values women as experts in their own lives enabled me to see how class, income, generation and support were reaffirmed and influenced variation in the emergent theory of Attentive Surveillance. Self-identified English speaking women residing in New Brunswick, living separately from their abusive partner for at least 3 months but abused when their child 6 years or younger, were interviewed.

This oral presentation, will present: (1) the theory of Attentive Surveillance, the basic social process employed by women mothering through IPV to manage the central problem of underachieving; and (2), strengths of a feminist intersectional qualitative grounded theory approach. While the central problem is not solved, the process of attentive surveillance provides a lens through which mothering in the context of IPV and a woman's management of underachieving can be examined and better understood. This theory has implications for health and social programs and policy in order to support mothers' existing capacities to foster mother-child relationships and healthy child outcomes in the context of the many challenges of IPV.

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## Behind the Back of Language? Hermeneutics, Critical Theory, and Qualitative Research

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Qualitative research in health and health care steadily draws upon methodological perspectives situated within both Hermeneutics and Critical Social Theory as orientations to inquiry. Exploring the philosophical and methodological tensions between such popular methodological orientations will not only foster rigour in our approaches to inquiry, but can provide unique insight into new methodological innovations that arise out of the resonance and interplay between such juxtaposed philosophical perspectives. The purpose of this paper is to explore the implications of the ongoing debate between Hermeneutics and Critical Social Theory for engaging in qualitative health research. We view the essence of this debate as a clash of beliefs regarding the nature of meaning and the possibility of understanding meaning in inquiry. The paper will begin with an outline of exchanges between the primary participants in this ongoing debate, including the exchange between Jurgen Habermas and Hans-Georg Gadamer, and between Thomas McCarthy and Richard Rorty. In addressing the various re-presentations of “meaning” and the processes of achieving meaning presented in these exchanges, we consider the implications of being either “Critical” or “Hermeneutical” with respect to the practice of qualitative research. We then provide an analysis and critique of both sides of this debate, exploring the philosophical assumptions integrated into each perspective with respect to the nature of meaning and understanding. After outlining the central role that judgments about language play in “choosing a side” in this debate, we explore potential avenues for innovative methodological orientations arising out of our analysis and critique.

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## Beyond the Pink Ribbon

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Historically, cancer survivorship has been reserved as a term for those who lived five years or longer without signs of cancer. Now the term survivor is used from diagnosis through the balance of a person’s life. Breast cancer survivors have been used as the primary examples of the survivor movement. The dominant cultural representation of breast cancer survivor is one of a triumphant, happy, healthy and feminine woman holding a place of honor in the cancer world. Women are expected to share the experience and present an optimistic picture of the outcome of treatment. The literature is replete with information about the various aspects of being a breast cancer survivor. But a paucity of information exists about what meaning is ascribed to the experience of breast cancer. The embodiment of breast cancer survivorship is rooted in cultural expectations, which may or may not be congruent with the

individual's perceptions or needs. Moreover, the disease or its treatment may have long-term effects that are unexpected or their severity under estimated.

Using interpretive phenomenological study, I explored the experiences of women whose treatment for breast cancer had been completed for 5 or more years, meanings ascribed to the experience, and the impact of long term effects on the survivor identity. A semi-structured interview guide was used to interview 15 women. Women in this study reported making positive lifestyle changes, stronger relationships, varied corporal concerns with varied severity, and concern about the commercialization of breast cancer.

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### **Boundary Negotiations in Living a Professional Life: Care of the Self and Others**

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This paper presents findings of research on discursive practices associated with professional boundary management. Boundaries are one of the primary concepts used to define the form and purpose of appropriate professional relationships where clarity of purpose, conservation of physical and emotional energy, and the ordering of spaces between professional work and private lives, protects both practitioners and the people they work with. Professional discourse constructs boundary management as typically shaped by distance, objectivity and the authority of professional expertise to define and manage problems on the other person's behalf and act in their best interests (Mellow, 2005).

The research approach used Foucault's (1984/1992) writing on ethics to analyse how professional subjectivity is negotiated and performed through discursive practices associated with the management of professional boundaries. The research method borrowed from the genre of autoethnography to examine one practitioner's experience of living and working within a region of New Zealand where one's community of practice frequently coincides with family commitments and social activities, within relatively small populations. The findings indicate three central elements in the discursive practice of professional boundary management, including normalising lines or limits, practising with zones of therapeutic helpfulness and relationship negotiation in context. Boundary negotiations are practised as strategies for critique, reinvention and repositioning of the professional self that are always subject to the discursive constraints and possibilities of power. Professional subjectivity becomes apparent as constant negotiations of relationships between self and others within the normative values that guide considerations about therapeutic purpose, boundary limits and exchanges.

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### **Breastfeeding Policy and Obstacles in Mexico**

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Breastfeeding rates in Mexico are still far below any reasonable expectation. Although general surveys report rates up to 20%, more accurate inquiries find them down to 2% for exclusive breastfeeding.

More than 20 years ago, the Baby Friendly Hospital Initiative reached the Country and its largest health organization embraced the scheme. All its hospitals were certified as 'Baby and Mother Friendly' and a variety of practices were implemented in hospitals all over the Country. However, the actual impact of all these on breastfeeding rates was minimal.

The present study set out to find out the explanation for this set back. We interviewed 29 pregnant women and mothers. We also made our data by interviewing the Mother and Infant nurses and other hospital staff appointed to carry out the "ten steps to successful breastfeeding", hospital authorities and, finally, a member of the staff in charge of the certification procedure.

The BFHI was designed to take hospital obstacles out of the way of mothers who were already personally motivated, technically informed and culturally supported, to breastfeed. Successful mothers in many Countries were informed and encouraged, but the basic drive was already in them. On the other hand, Mexican mothers were neither determined nor encouraged or supported by a critical mass of peers and their breastfeeding hardly reached the day of discharge.

We suggest a thorough examination of the issue in order to aid in the design of and test a culturally sound strategy to increase breastfeeding rates in Mexico.

### **Can We Improve Workplace Health during an Economic Recession?: A Qualitative Investigation of Managers in Greater Manchester, UK**

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During the current worldwide economic recession, there is an increased need to manage the existing workforce well in order to maximise organisational effectiveness. Managers have an integral part to play in the implementation of this agenda, although there is little evidence regarding the support available to them, in managing health at work. This paper presents the findings from a large qualitative study of senior and middle managers from three large organisations in Greater Manchester, UK (n=40). Current practice in managing sickness absence, health and wellbeing of staff was investigated, with the ultimate aim of informing the development of training for managers.

Key findings were that managing absenteeism is a complex task, and requires the appropriate policies, skills and tools to support managers. Wellbeing of staff was seen as being achieved through the provision of individual health promoting interventions rather than an integral part of the organisational context. Findings from this study indicated a two-tier system of support for managers was required with a greater emphasis at senior management level. The health of staff needed to be incorporated into business planning, and a supportive policy environment created, before middle managers could effectively manage the health and wellbeing of staff.

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### **Challenges in Obligatory Supervision of Student Radiographers during Their Clinical Practice**

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The aim of the study is to describe the radiographers challenge when supervising student radiographers during clinical practice in the radiology department.

Grounded theory was used to gather and analyze data from three different focus groups: junior radiographers, senior radiographers and section leaders. The interviews were tape-recorded and transcribed verbatim.

The main challenge reported was how to handle the burden of obligatory supervision. Two patterns of lessening the burden are identified:

1. *Externalizing* the burden by blaming the department, students and educational institution. The consequences of externalizing the burden are: lack of will to supervise, perception of stress and strained workload, and sense of duty rather than motivation.
2. *Embracing the burden* by integrating supervision in the work of the department, creating a safe atmosphere for supervising, requesting support from the college and looking for rewards. The consequences of embracing the burden are: will to supervise, professional growth, development

of professional pride, promoting of professional quality, and increased motivation for supervision.

Handling the obligatory supervision of student radiographers is recognized mostly either as a burden or a resource. It is important to develop a job culture where supervision is a valued and integrated component of the work of the department, and the will to supervise is present.

The developed conceptualization is used for quality improvement and development of evidence based supervision in the Department of Radiology.

### **Check Up on Cultural Safety: Aboriginal Peoples' Perspectives about Health Care in a BC Hospital**

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Evidence demonstrating that the current health care system and health practices are not working for Aboriginal people living in Canada, has prompted efforts to introduce strategies to improve health care services including training on cultural safety, Aboriginal patient navigators, and spaces in hospitals for traditional ceremonies such as smudging. To guide the further development of healthcare services for Aboriginal people, we undertook research aimed at understanding how current health care delivery systems and organizational structures contribute to experiences of culturally safe and unsafe healthcare for Aboriginal people. By grounding the study with the concept of cultural safety attention was directed to experiences of health care relations not simply as relations between individuals (health care provider and user), but rather as social and structural power relations from the perspective of Aboriginal peoples. As part of this project, 28 Aboriginal peoples who received health care at a hospital British Columbia (BC) were interviewed about their experiences. Thematic analysis resulted in the identification of

themes related to culturally unsafe and safe care. Culturally unsafe care is detailed in relation to rules and policies, interpersonal relations, racialized constructions of the patient/family, and ways of being in culturally unsafe health care environments. Perspectives on the provision of culturally safe care are described. These findings are interpreted within the organizational and policy context in BC, and indicate that despite efforts to enhance Aboriginal health services in BC experiences of culturally unsafe care persist. Directions for effecting organizational change to influence the delivery of culturally safe and accessible health care are discussed.

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### **Chemotherapy Closer to Home – Patients’ Perspectives of Receiving Chemotherapy in Outpatient Clinic and/or Onboard a Unique Mobile Chemotherapy Unit**

Theresa Mitchell

*University of West England*

In the United Kingdom there is a drive to revise chemotherapy provision for people who live in rural communities. In 2007 the first nurse-led mobile chemotherapy unit (MCU) was launched in Gloucestershire, England with the intention of providing treatment closer to home.

Fourteen women and six men participated in the study with an age range of 46 to 76 years. An Interpretive Phenomenological approach was employed and conversational interviews were conducted in the homes of participants. Often a spouse or partner was involved in co creating the data and this contributed to the data being contextually bound. Interviews were digitally recorded, transcribed and data were thematically analysed.

The treatment journey was described as being undertaken by both the participant and their significant other. Car parking and travelling impacted upon quality of life, as did the environment and accessibility of nurses to discuss issues with participants. The most important, distinguishing feature between receiving chemotherapy in outpatient clinic and the MCU was the amount of time spent waiting. Having treatment on the MCU was perceived to be less formal and therefore less stressful. Costs to participants were significantly reduced in terms of travelling, waiting and having treatment, expenditure on fuel and companion costs.

The MCU offers an alternative model for chemotherapy delivery that is highly acceptable to people with cancer and as it is the first in the UK it is likely to be of worldwide interest to organisations that aspire to the provision of chemotherapy closer to home.

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### **Clinical Implications of Infant Thermal Care Practices and Beliefs in a Bi-Ethnic Population**

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Infants are born with immature thermoregulation and a high risk of fatal or serious temperature related complications such as sudden infant death syndrome, infections and neonatal hypothermia. Infant thermal care depends on several physiological, environmental and behavioural factors. Little attention has been paid to infant thermal care beliefs practices, for example humoral beliefs, common globally, that prescribe thermal balance to maintain health. This study employed a mixed methods approach to explore differences in infant thermal care beliefs and practices of 102 white British and South Asian mothers in Bradford, West Yorkshire, England. White British mothers were found to use significantly ( $p=0.001$ ) more bedding in winter for their infants than South Asian mothers. White British and South Asian infants were found to sleep in different environmental conditions. Mothers used several physical and behavioural cues to identify thermal stress in their infants and reported multiple infant health problems caused by heat stress and cold stress. White British mothers were significantly more likely ( $p < 0.0001$ ) to be concerned about their infant getting too hot than too cold and South Asian mothers about both. This study demonstrates thermoregulation of infants cannot be removed from the thermal care behaviour and beliefs of their caregivers. By exploring health beliefs and practices in other cultures, bias in the choice and focus of clinical research in the UK can be understood and addressed and future directions for research and policy.

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### **Collaborative Research on Service Redesign in Hospitals: Strategies for Improving Knowledge Translation**

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The National Institute for Health Research (NIHR) funded nine Collaborations for Leadership in Applied Health Research & Care (CLAHRC) projects in England whose purpose is to explore the translation of evidence into practice in the NHS by conducting high quality applied health research. Theme 1 of the Birmingham & Black Country CLAHRC is tracking the strategic direction and several clinical 'tracer' services over time in three Acute NHS Trusts to measure how they incorporate change.

The research uses 'mixed methods' combining qualitative approaches (e.g. semi-structured interviews) with more quantitative analyses using routine activity data. 77 senior managers and clinicians were interviewed in 2009 to understand the Trusts' strategic direction, with a smaller number re-interviewed in late 2010, and again during 2012. Two rounds of interviews with staff involved in the 'tracer' pathways are also being carried out, and one round of patient interviews. Messages from these are then being 'triangulated' against routinely collected activity data. The lessons of such a 'co-production' approach are beginning to be published.

Collaboration with patient representatives, clinicians and other senior stakeholders has been fundamental to our approach; the clinical 'tracer' services were chosen to reinforce this. Knowledge mobilisation amongst these stakeholders occurs in several ways including regular updates, formal formative feedback, and synthesis of the emerging lessons and the manner in which NHS bodies assimilate them; some have been more successful than others, and this presentation will explore the different approaches utilised in the CLAHRC study, highlighting the facilitators and barriers to their utility.

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### **Communicating the Value of Experiential Knowledge: Personal Stories of Mental Illness**

#### **Online**

Monique Solomon

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Qualitative health research is more than an evaluative tool for assessing existing approaches in health care. The challenge in future is to better communicate the primary value of experiential knowledge as a basis and guide for creating programs and collaborative partnerships with consumers. Methodologically there are opportunities to take qualitative analyses beyond description and interpretation. This requires bolder questions about how descriptions and interpretations of health experience maintain or challenge the status quo. It means carefully examining how existing and potential approaches relate to various contexts in which particular experiences are situated. Theoretically this signals a need for greater reflexivity and reflection on how experiential knowledge is valued, expressed and communicated. Using narrative approaches, qualitative health researchers have demonstrated that description and interpretation of experience are substantive influences on changing health care practices, policy and education. Examining personal stories about illnesses such as Cancer, HIV/AIDS, and Multiple Sclerosis has provided strategic and tactical information about how to better address social and clinical issues. However, personal stories about mental illness have not been as highly regarded as influential sources of knowledge. In this presentation I discuss how qualitative research on personal stories of mental illness posted on consumer/survivor websites is an essential and significant catalyst and contributor to mental health care.

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## Concatenation and Generalizability in Qualitative Research

Mohamed El Hussein

*Mount Royal University*

Considering the small sample size and the nature of qualitative research, external validity or generalizability can be considered a limitation. The issue of generalization is less frequently discussed in qualitative research, and is considered complicated and controversial, as the main goal of qualitative research is to provide rich and contextualized understanding of the human experience. However, qualitative traditions that are based on exploration (Grounded Theory) have a unique feature of potentially being able to extrapolate its qualitative findings. This feature is due to the nature of exploration and its ability to reveal high-level concepts and theories that are not specific to a particular participant or setting. Several authors argued that just as with statistical analysis, the end product of qualitative analysis is generalization, regardless of the language used to describe it. The main goal of exploratory research is the production of inductively derived generalizations about the group, process, activity, or situation under study. Concatenated exploration is a process that will refute the charge that qualitative research consists chiefly of ungeneralizable case studies. If a competent exploration is performed, it is very unlikely that generalizations emerging from it will be falsified especially if the subsequent trials to verify them are done on the same population and processes, which eventually leads to broadening and extending the scope of the ever-emerging grounded theory.

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## Confessions of Postpartum Depression: Discourse Analysis of an Internet Forum

Ira Kantrowitz-Gordon

*Washington State University College of Nursing*

*University of Washington School of Nursing*

Postpartum depression (PPD) is a condition that affects approximately 15% of new mothers. PPD bears the double stigma of mental illness and failure to be a good mother. Many mothers suffer in silence due to reluctance by both healthcare providers and mothers to discuss this sensitive issue. It is therefore important to consider how mothers are able to talk about PPD and what discursive strategies they use. Foucault introduced the idea that confession is a widespread technique for producing truth in Western societies. This confessing society has extended to the internet and online social media. Confession is a useful framework for examining how mothers may discuss their experiences of PPD outside their relationships with family, friends, and healthcare providers. One venue for such discussions is the public internet forum, in which mothers may share their experiences, advice, and support. An internet forum, I Had Postpartum Depression ([www.experienceproject.com](http://www.experienceproject.com)), displays in the public domain stories by women who have experienced postpartum depression. A discourse analysis was conducted on a corpus of 53 primary posts and responses available on the site in March 2012. Mothers used multiple linguistic strategies in their posts on PPD. These included confessional language, self-judgments, disconnected

mothering, shame, and disembodiment. This study has implications for creating safe spaces for mothers to discuss PPD and seek help in conventional and electronic interactions.

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### **Constructing the Processes and indicators Utilized by Registered Nurses (RNs) to Recognize Delirium in Older Adults in Acute Care Settings**

Mohamed El Hussein

*Mount Royal University*

The purpose of my study is to describe, conceptualize, and develop an explanatory theory of the processes involved to recognize delirium in older adults. Constructivist Grounded theory method, described by Kathy Charmaz will be used in this study. The choice of the grounded theory method for the study is determined by the research question, along with consideration of the applicability and feasibility of the method in the context of the phenomena of interest "recognition of delirium". Grounded theory is particularly applicable for exploring "recognition of delirium" due to the nature of this phenomenon and its deep roots and relatedness to nursing practice. This phenomenon is not quantifiable, as it focuses on the responses of the RNs who are involved and interacting with older adults to understand the complicated social processes of the phenomenon. The research approach is based on the grounded theory tradition, which includes theoretical sampling, constant comparative, coding and categorizing, memo writing, and theory generation. This research is timely and will have far-reaching applications because the study will construct the processes utilized by RNs to recognize delirium. This research has its potential to impact the nursing care of older adults and ultimately promote positive health outcomes. With knowledge gained through findings from this study, researchers will be better equipped to focus on developing interventions to increase nurses' recognition, prompting earlier detection and management of delirium. The findings will aid nurse educators to better prepare their students and practicing nurses to assess, document, and care for older patients with delirium.

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### **Creating Simulations to Build and Enhance Interdisciplinary Leadership Team Training and Relationships in Graduate Healthcare Education**

Lydia Forsythe

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*Walden University*

*Londes Strategic Healthcare Consulting*

Purpose:

Creating simulations in the graduate healthcare education setting to build and enhance interdisciplinary leadership team training and relationships will define a new and constructive mechanism for leadership and management training. This training is based in the notion of sustainable leadership and accountable

care organization were the organization is leaderful and at every level of the organization people need to have the experience of leading and importantly sensing that their contributions matter.

Methods:

Designing qualitative simulations using a modified action research cycle where situations are reflected upon in the immediate time with a facilitated discussion to coordinate meaning can result in improved interactions for positive and constructive decision-making resulting in the betterment of patient outcomes. The participants design a scenario they want to role play and then as the situation unfolds the team explores the various aspects of how to mindfully reflect upon the positive and negative within the communication interaction to proceed with a coordination of meaning.

Results:

By creating leadership simulations in a graduate education program for interdisciplinary communication we will give our students a safe zone to practice collaborative interactions where they can define positive and effective communication strategies.

Conclusion:

Using the theoretical ideas from the Coordinated Management of Meaning (CMM), the concepts of sustainable leadership and the notion that we build our relationships as a social construction gives us a curriculum model and structure to practice reflective communication where conversations are defined as systems of communication to improve interdisciplinary care.

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### **Data Collection and Analysis as a Text-Mediated Work Process: Mapping Mixed-Methods HIV/AIDS Research with Gay and Bisexual Men**

Daniel Grace

*University of British Columbia*

Malcolm Steinberg

*BC Centre for Disease Control*

Michael Kwag

*BC Centre for Disease Control*

We use a social organization of knowledge perspective to map the production and dissemination of research evidence in a longitudinal study of self-identified gay and bisexual men in Vancouver, British Columbia. These men (n=169) recently had an HIV test and reported a negative result. All of the men participated in the quantitative components of the study and a subsample (n=30) were invited to participate in concurrently running qualitative interviews. Three text-mediated work processes are mapped: (1) longitudinal quantitative and qualitative instrument design; (2) participant enrollment into the quantitative and qualitative study components; and (3) quantitative, qualitative and mixed-method analysis during and after data collection. This last work process is explored through an in-depth explication of our collaborative techniques for engaging a diverse research team in coding, modeling and analyzing men's complex, socially-embedded narratives of unprotected anal intercourse (UAI). We

highlight important methods issues that were examined through this process of collaborative analysis including: apparent contradictions within and across men's narratives; the self-reported impact of study participation on men's sexual activities; and the importance of reflexivity during the progression of data collection and analysis (e.g. considering how interviewers may be sexualized or adversely affected through conducting research). This cartographic exercise makes visible specific ways in which our study follows a mixed-methods research tradition and a commitment to community-engagement while identifying key issues for further consideration. We argue that engaging in similar reflexive mapping exercises may help strengthen research team's commitments to mixed-method research and community engagement during the research lifecycle.

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### **Defying the Odds: Growing Up & Growing Older with a Lifelong Physical Impairment (Cerebral Palsy)**

Laura Moll

*Ontario March of Dimes*

**Purpose:** The purpose of this presentation is to describe the Defying the Odds Narrative that emerged from my PhD. study on the experience of individuals who are aging with a lifelong physical impairment. **Method:** A qualitative methodology was utilized consisting of narrative inquiry informed by the Life Course Perspective. The life course perspective is a dynamic approach that encompasses multiple theories including sociology, human development, and aging, highlighting how social, historical, and cultural contexts shape people's lives. Narratives are storied ways of knowing and communicating that people use to organize events in their lives and make sense out of their experiences. Nine community-dwelling individuals (3 men; 6 women), aged 26-70, with mild to severe Cerebral Palsy were recruited using a combination of purposive and snowball sampling. Multiple (3-4), in-depth interviews were completed with each participant in order to co-construct their life stories. The data analysis was iterative. NVIVO 8 was used to organize the data, supporting a systematic comparison of emerging themes and categories, as well as the central plot that weaves the participants' experiences together. **Findings:** "Defying the Odds" emerged as the central narrative that weaved together their experience of growing up and growing older. Their narrative is depicted through the trajectory of the disordered body that manifests itself in peaks and valleys. Their narrative is also weaved together by three central threads: Achieving a Sense of Belonging, Overcoming being Seen but not Heard, and Striving for Self-Reliance. "Normalization" emerged as a key recurring theme in the participants' life stories. The focus of rehabilitation on "normalizing" movement, particularly walking, during childhood can lead to social psychological challenges as well as problems later in the life course as people encounter increasing fatigue and decreasing functional abilities but no longer have access to rehabilitation services. **Implications:** Theoretically, the disordered body needs to be reconceptualized in ways that are more positive. Conceptualizing a theory on aging with disability needs to be pursued. Clinically, we need to work towards developing a continuum of care across the life course with a focus on long-term maintenance and prevention of secondary health problems.

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## Developing a Model to Map Complexities to Qualitatively Analyze the Impact of Electronic Health Record Adoption on Interprofessional Collaboration

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Lara Varpio

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Kathy Day

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Electronic Health Records (EHRs) and interprofessional collaborative practice (ICP) each have considerable independent bodies of research supporting their use. However, little research has addressed where and how these fields intersect and interact. To address this gap, we conducted a longitudinal case study using a constructivist grounded theory approach, the aims of which were twofold. First, we sought to explore and describe ICP, specifically, before (phase 1), during and after (phase 2) the introduction of a new EHR. Second, we aimed to develop a theory of how healthcare professionals develop ICP skills when working with and through EHRs. Twenty-two patients together with their family members, recruited at one Canadian paediatric academic hospital, and 302 interprofessional healthcare providers who participated in their care were followed from their intensive care unit admission through transfer to a medical inpatient unit and to discharge. A triangulated data collection approach was used: observations of interprofessional exchanges concerning the patient, interviews, and think-aloud sessions associated with accessing EHR-based data. Based on Phase 1 findings, we modeled clinical ICP complexities. This model enabled us to locate, observe and analyse the impact of the new EHR on ICP within four contextual spheres: (i) across oral, electronic and paper communication genres; (ii) through a patient's passage across different units in the hospital; (iii) across the duration of the patient's stay in hospital; and iv) across multiple healthcare providers. We propose that this model can support analysis of the impacts of EHR adoption on ICPs in healthcare settings.

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## Developing and Using Pen Portraits as a Research Output: Maximizing the Impact of Qualitative Research Findings

Angela Tod

*Sheffield Hallam University*

Results of qualitative research are often difficult for researchers to summarize in a concise way that is accessible to those applying findings in policy and practice. The Keeping Warm in Later Life project (KWILLT), funded by the NIHR, demonstrates how using pen portraits as a research output helped to increase the impact of the findings. KWILLT explored factors influencing older people's abilities to keep warm. KWILLT examined the knowledge, beliefs and values of vulnerable older people regarding keeping warm at home. In-depth interviews (50 older people, 25 health and social care staff) were conducted with six focus groups. A structured consultation with strategic and front line professionals tested added rigour to the findings. Framework Analysis techniques were adopted. The study generated a unique understanding of the complex environment. Multiple factors emerged as influences on older people keeping warm and well in winter. These fell into three thematic groups, contextual factors, attitudinal drivers and barriers. Six pen portraits were developed from the findings that describe six groups of vulnerable older people who are at risk of being cold and ill for different reasons. The themes and method of developing the pen portraits will be outlined in the paper. The portraits are a tangible, engaging and accessible way for people at policy, strategic and clinical levels to understand the lives of people at risk and identify action to address the issue raised. Applications of the pen portraits include e-learning and vimeos to provide accessible resources for different audiences.

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## Development and Evaluation of a Research-based Prosthodontic Clinical Record

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Patient's dental records contain valuable information that would give clinical researchers an opportunity to use a wide range of quantitative or qualitative information. Standardization of clinical record would allow the interoperability and reusability of data in different research fields. The aim of this study was to

design a research-based patient record in the field of removable prosthodontics in the undergraduate clinic of the “Université de Montréal.”

This study used action research methods with 4 sequential steps: problem identification, gathering and interpreting data, action planning, and action evaluation. Study participants included professors, clinical researchers, and clinical instructors in the field of removable prosthodontics. Data collection consisted of a comprehensive literature review on prosthodontic outcomes as well as focus-group discussions and interviews. The qualitative data were analysed using QDA Miner 3.2.3. The study participants raised several concerns about the deficiencies of the existing patients’ prosthodontic record in the undergraduate clinic. They shared their ideas for designing a new patient record based on 3 key objectives: clinical, educational, and research objectives. The prosthodontic outcomes of interest and appropriate instruments as well as the clinical parameters were selected by the research group and were integrated into a new research-based record. The appropriateness of the new record has been evaluated by the same panel of experts and the necessary modifications have been carried out. The study participants agreed that the action research cycle should be continued to evaluate the feasibility of the implementation of this redesigned record in the university-based setting.

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### **Dewey’s Pragmatism Offers a Way of Exploring ‘Consequences’**

Shelaine Zambas

*Auckland University of Technology*

How do you explore the benefit of a nurse using advanced assessment skills within the complex health care environment of an acute care ward? That is the question I grappled with, trying to find an appropriate methodological approach. My aim was to ask what practical difference did use of advanced assessment skills make to individual patient outcomes in the acute care setting. Linking specific actions to outcomes in the health care setting is challenging. Patient outcomes are varied and influenced by a myriad of factors, and always involve a wider team than any one nurse. It is difficult to control for a single action or set of actions of a particular nurse. Further, practice is seldom about any ‘one’ action, for one thing leads to another, all within a complex interplay of influencing factors. This presentation will describe the journey towards choosing a methodology which combines Dewey’s pragmatism with Gadamer’s hermeneutics; a combination which allows for recognition of the experience of an individual’s practice by interpreting their stories of consequences. This methodological approach allows the complex interplay of influences to be revealed in the unfolding story. Reflection of the nurse brings insights that may otherwise have been passed over. The philosophical notions of Dewey draw attention to the play of ‘means’ and ‘ends’. A hermeneutic approach that calls for ‘thinking’ extends understanding and raises insights that can inform education and practice.

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## **Dialoguing with Our "Selves": Reflexive Questions for the Anti-Oppressive, Embodied and Relational Researcher**

Darla Fortune

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Susan Arai

*University of Waterloo*

This paper explores layers of reflexive process in research and engages a dialogue about what we share in texts we create. We advocate for a view of reflexivity as relational and imbued with emotion, power, and difference. Drawing from our experiences as researchers working for social justice; mainly from our work on community inclusion and research with women federally incarcerated in Canada, we discuss how a relational and anti-oppressive stance to reflexivity means we grapple with decentring our assumptions and perspectives on the world to join participants in creating understanding.

This presentation illuminates three layers of reflexivity. First, we argue for a reflexive portrayal of self to address how researchers' multiple selves shape the construction of knowledge. Second, we show how the reflexive process requires us to explore ways our embodied emotions shape research processes. This includes a return of the body to research and the ways that negotiating markers on the body shape research processes. Third, using relational theory we focus attention on power relations between people engaged in research, including between researcher and audience.

Our intention is to further dialogue about complexities inherent in research processes. We speak candidly about challenges we encountered while engaging in research because we believe knowledge from challenges in one project may be used to guide another project toward more inclusive processes. It is our hope that each time we discuss tensions, expose our vulnerabilities, and share our rewards and challenges we contribute to a collective movement toward social justice in research practices.

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## **Digital-Vignette: Moving With and Through the Qualitative Research Paradigm and Aesthetic Values**

Manuela Ferrari

*University of Toronto*

Shawn Carnegie

*Director of Photography, Film and Video*

This paper presents *digital-vignette*, short digital videos, as a new analytic device to capture the interpretation of qualitative data in an evocative episode able to promote personal awareness, reflexive practice, and stimulate dialogue among health practitioners. During the presentation, three digital-vignettes, developed using the Beyond Obesity and Disordered Eating in Youth (BODY) study data, a qualitative project aimed at exploring the discourses that circulate regarding the relationship between

the eating disorders and obesity prevention fields, will be shown to the audience to describe and discuss the value and insights of this new analytic device. BODY study data has been collected across Canada through interviews conducted with 35 practitioners who work in either eating disorders or obesity (for a total of 55 in-depth interviews), six focus groups and 12 in-depth interviews conducted with 26 youth. Within digital-vignettes, quotations are combined together to compose a script that represents the research themes. Final data interpretation is depicted through the characters, set decorations, light, and music, which describes the data theorization. The presentation aims are as follows: First, to discussing the process of moving with and through the qualitative research paradigm and aesthetic values as a way for creating, perceiving and responding to qualitative data, its visual representations, emotionally as well as aesthetically; Second, to show how a digital-vignette can foster critical self-reflection and constructive dialogue among health professionals, so that they can share knowledge and deliver health promotion strategies in an informed and integrated way.

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### **Discourse Analysis and Qualitative Evidence: Reflections on a Study about Clinical Supervision in Nursing Education**

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Katie Eriksson

*Åbo Akademi University*

Carola Wärnå-Furu

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The aim of the study is to explore clinical supervision as a teaching-learning activity and to develop a tentative theoretical model. The research questions are: *What discourses are uncovered in clinical supervision? How do the participants interact and position each other? Why is the clinical world constructed and represented in certain ways?* The research paradigm is qualitative seeing nursing education in a caring science and humanistic 'Bildung' perspective, learning in a socio-cultural perspective and using discourse analysis as the methodological approach. Approaches to qualitative evidence will be presented. The participants in the study are students, clinical preceptors and university college teachers purposively selected from different levels and clinical contexts in the bachelor program. The data material consists of supervisory talks in dyads and triads, individual and focus group interviews, 'critical incident' narratives and formal documents. Findings from the talks indicate that: 1) representations of the clinical world are 'multiple', 2) two main discourses are framing the talks, one about 'caring' and one about 'learning', 3) a hierarchy of voices are uncovered in the interaction and 4) a 'theory-practice gap' is present positioning 'theory' as dominant. These findings indicate a limited conception of the educative process as 'Bildung'. The conception of caring science is mainly cognitive thus ignoring the dimensions of practice, ethics and esthetics. The findings will be discussed in relation to qualitative evidence taking the true, the good and the beautiful as a basis for knowledge development in caring science.

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## Doing Technological Time in a Pediatric Hemodialysis Unit: A Ethnography of Children

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Since the 1960s, hemodialysis has been a common intervention for children with end-stage renal disease and usually is received in a specialized ambulatory hospital-based unit. For weeks, months or years, children's activities are disrupted because they must return to the hospital to be dialyzed about three times a week, for three or four hours. Their childhoods are characterized by temporal disruptions, socio-spatial dislocations and technological dependence. Little is known about how children perceive and respond to hospital-based hemodialysis.

A focused ethnography, involving participant observation methods (structured observations, focused interactions, and guided activities) with eleven children, between 7 to 17 years of age, who receive maintenance hemodialysis, was undertaken at a Canadian urban pediatric hospital to describe and interpret the children's embodied situatedness. Time, space and technology were viewed as significant interrelated aspects of the unit and the unit was conceived as nested in the broader life contexts of the children. The theoretical framework merged concepts of human embodiment, human geographical and temporal perspectives and philosophy of technology.

A dominant theme emerging from the study findings was the notion of the children doing technological time, which had far-reaching effects across their daily routines outside of the unit. The children's experiences of their technologically mediated embodiment in the unit shaped their perspectives, evaluations and expectations. The children's accounts suggest that crucial changes in practices and policies are essential to envision ways to create with children an overall positive place that merges and balances technological care with child focused care.

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## Engagement and Use of Qualitative Methods to Foster Change In Health Care Practice and Policy

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The Alberta's Caring for Diabetes (ABCD) project seeks to improve the quality and efficiency of diabetes care in Alberta. It includes the piloting of quality-improvement interventions in four Primary Care Networks for people with type 2 diabetes. Using a mixed-methods approach, our team adopted the RE-AIM evaluation framework to determine the interventions' public health impact beyond clinical effectiveness. The qualitative components of our research design and evaluation framework are instrumental in informing target audiences to foster change in health care practice and policy.

The engagement of knowledge users is fundamental to moving beyond mere description and interpretation of the effectiveness of health interventions. To achieve this, we identify and collaborate with key stakeholders in the form of advisory committees. Committee members include target audiences, such as local policy and decision-makers, who are keenly interested in the study and evaluation findings. In addition, the RE-AIM evaluation framework provides a means to structure our evaluation plans and dissemination of findings. For example, we are better able to disseminate digestible portions of our qualitative findings by focusing on each dimension of RE-AIM. This allows us to provide target audiences with appropriate messaging, thus enhancing the opportunity to advance policy.

In this presentation, we outline our process for engaging knowledge users and the use of the RE-AIM model to structure the dissemination of research and evaluation findings as means to promote the use of qualitative findings in changing health care practices and policy.

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### **Ethnographic Exemplars of End-of-Life Decision Making in Adult ICUs**

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Judith G. Baggs  
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Sally A. Norton  
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In this secondary analysis of data from a larger study of end-of-life decision making (EOLDM) in adult ICUs we examined the effects of advance directives (ADs) on EOLDM in the ICU setting. The original study was set in 4 different adult ICUs (burn/trauma, cardiovascular, medical, surgical), in an academic healthcare center in the northeastern US. ICU patients were predominantly female (62%) and White (85%); the mean age was 71 (SD=14; range=27-91) years. There were 157 interviews with 130 participants including patients and family members, nurses, physicians, social workers, and other healthcare professionals.

Using ethnographic methods, we created 33 cases (comprised of transcripts of field observations and in-depth, semi structured individual interviews, and advance directives documents and family meetings when available) of EOLDM surrounding a patient. The cases served as the unit of analysis and analysis occurred both within and across cases.

Fifty-two percent of patients had an AD on admission to the ICU. Fewer than 10% of the patients participated in contemporaneous decision-making. Cross-case analysis revealed cases where ADs were present or absent, but were variably helpful or not helpful. Exemplar (composite) cases of these scenarios were then created to illustrate this variation.

ADs are often encountered in the adult ICU setting. They may facilitate EOLDM or have no effect on or even hinder EOLDM. These exemplar scenarios are reviewed and implications for future research and practice are suggested.

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### **Evolution or Revolution: One story of Health Homes Program Development in the US**

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In the United States the unfolding of the Federal Patient Protection and Affordable Health Care Act (2010) is resulting in rapid and important changes as state and counties reorganize to meet new mandates. One example is Health Homes intended to provide a cost saving model and approach that offers patient-centered care, focusing on primary care, prevention and health rather than an acute care illness model. This represents an abrupt change in philosophy of care, and role of providers, impacting agencies and staff who work with affected populations.

The New York State Department of Health (NYSDOH) elected to move in this direction for individuals with chronic mental illness. Transitioning requires agencies to provide requisite knowledge for staff in

their role change, and work with clients to identify their understanding of and response to Health Homes and their perceptions of services and desired outcomes. While there is ample literature on Health Home little has been written on methodologies for implementation of this new model.

Declining a top down approach for education, a county mental health agency partnered with an area college to form a community of practice, and Participatory Action Research (PAR) was used as an approach for organizational change to address issues, problem solve, and decide on educational needs. The target population for this project was twofold, current case managers and clients served by the agency. Data was collected through focus groups.

Results highlight the use of PAR for health program development, as well as explication of much unanticipated education needs.

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### **Experiences of Family Caregiving for Adults with Chronic Physical Illness**

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Susan Law

*St. Mary's Hospital*

Tabitha Tonsaker

*St. Mary's Hospital*

Finding health information is one of the primary reasons why people access the internet, yet there are concerns about the quality of web-based resources, i.e. the extent to which they are evidence-based or representative of the range of lived experiences with different health problems or concerns. A team at Oxford University has developed a highly successful, award-winning initiative where people can find reliable health information on the web based on rigorous qualitative data. A St. Mary's-McGill research team has become a member of the international collaboration based on this initiative with the first Canadian module focusing on caregiving for adults with a chronic illness. The burden of caregiving and the enormous contribution of informal caregiving to our healthcare system is an important topic in the overall quality, cost, equity and effectiveness of healthcare delivery.

Qualitative semi-structured audio or video-recorded interviews are conducted with approximately 40 caregivers across Canada for a maximum variation sample. The analysis and results include the identification 25 topic summaries on matters important to participants, illustrated with audio, video and text clips.

The [www.healthexperiences.ca](http://www.healthexperiences.ca) / [www.experiencessante.ca](http://www.experiencessante.ca) sites are unique in Canada in the field of patient-centered healthcare communication and will be launched with the completion of the caregiving module in the Fall 2012. This will contribute key messages for other caregivers, professionals and policy makers about the caregivers' perspective on caring for adults with chronic physical illness.

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## Exploring How Service Setting Factors Influence Practice of Critical Time Intervention

Fang-pei Chen

*Columbia University School of Social Work*

Service setting characteristics often influence knowledge translation of community-based treatment programs. Community programs supported by scientific evidence usually have guidelines for program structure and components but no standardized practice instructions in order to accommodate complex cases in various settings. However, variation in practice may have significant implications on program fidelity and outcomes. This study seeks to identify service setting factors and their influences on practice of Critical Time Intervention (CTI), an evidence-based community psychiatric rehabilitation program designed to reduce homelessness among people with mental illness.

I applied grounded theory to explore practice experiences of three CTI practitioners in a clinical trial research setting and nine practitioners in four community agencies. The grounded theory methodology holds that perspectives and human actions are fundamentally influenced by contexts and social interactions. The use of this methodology thus helped to develop a CTI practice model that incorporated contextual influences. In constructing the conditional/consequential matrix, I identified key factors among the five settings that altered CTI practice. Service structure (including a platform for relationship building, staff for housing applications, and organizational approaches to substance abuse) and agency services (including existing resources and modalities) greatly influenced CTI practitioners' operationalization of shared CTI goals and fundamental practice strategies.

Findings indicate significant contextual factors derived from practice experiences, inform additional CTI fidelity elements, and suggest essential assessment of service settings for CTI implementation. The study highlights the crucial role of practitioners in implementing evidence-based programs, and the significant contribution of the grounded theory methodology to enhancing knowledge translation.

Acknowledgement: The manuscript has been published in *Journal of the Society for Social Work and Research*, 3(1), 51-64. doi:10.5243/jsswr.2012.4

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## Facilitating New Directions in Health Promotion with a First Nations Community: Findings of Two Ethnographic Studies

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Roberta Woodgate

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Sarah Lazar

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To reduce health disparities, researchers must examine the underlying determinants and context shaping health by partnering with First Nations Peoples. Two ethnographic studies were conducted to identify significant needs in family health from the perspectives of health care providers and community members in a First Nations community located in Western Canada. In this oral presentation, we compare and contrast the perspectives of health care providers with community members by using proximal and distal components of community health as a guiding framework. Health care providers tended to focus on the proximal determinants of health to identify significant family health needs. Health care providers consistently shared their concern for community members to “eat better” and “exercise more.” Community members were more apt to view family health needs using the broader, distal determinants of health. These findings were shared with community leaders to provide new directions for family health promotion programs.

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### **Finding the Edges: Challenges of Case Study Research in Emergent Social Systems**

James Conklin

*Concordia University*

Anitha Kothari

*University of Western Ontario*

Paul Stolee

*University of Waterloo*

One of the first case studies carried out through the research program entitled “Knowledge to Action Processes in SHRTN Collaborative Communities of Practice” concerned the “Behavioural Support Systems Learning Collaborative” initiative being carried out by the Mental Health, Addictions and Behavioural Issues community of practice. Initiative leaders were embedded in a variety of overlapping social contexts, were involved in numerous programs and initiatives, and each framed the case in different ways. As a result, investigators encountered a problem in defining the boundaries of the case, and in understanding the main components and processes within the case. It proved challenging to maintain a sense of coherence about the events being studied. This abstract/presentation highlights specific examples of this difficulty, and shows the strategies used by the investigators to remain open to ambiguity while maintaining a sense of the bounded coherence of the case. This tension became an occasion for the investigators to consider a middle ground between case study research intended to generate theory and hypotheses, and case study research intended to confirm theories and explain phenomena.

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### **Giving a Voice to Advanced Practice Nursing Through Storied Experience in Practice**

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Sandra Weiland

*Texas Woman's University*

Patricia Holden Huchton

*Texas Woman's University*

Qualitative research is suited to research seeking to give voice to advanced practice nursing. Two such studies were conducted in 2010 and 2011 with common themes identified in the narratives. One study used narrative inquiry exploring understandings and meanings of the nurse practitioner's professional experience in providing health promotion—the focus was prehypertension. In this study, seeking to understand meaning of NPs' experiences with a particular event, temporality was a central feature. Using the three-dimensional narrative inquiry space during data analysis allowed the researcher to view the temporal aspect of the storied experience as something that has happened over time and to organize the NP's experiences into temporally meaningful episodes. The personal/social interaction was also important as the co-dependency between the two contextualized all aspects of the NP's experience in their practice environments, or place.

The second study incorporated Gadamerian hermeneutics as the methodological framework to understand the meaning of autonomy as interpreted by NPs in their everyday practice. Because NP autonomy concerns gender and marginalization, Carol Gilligan's theoretical argument that the fusion of identity- and intimacy-formation is defined through relationships, guided understanding and interpretation of the meaning of NP autonomy. The complexity of interpretation involving the hermeneutic circle and developing understanding through the fusion of horizons evolved through conversations between NP and researcher as well as text and researcher. Intellectual openness, allowing the text to assert its own truth, and truly listening to the other in genuine conversation revealed Genuine NP Practice to emerge as the overall interpretation.

### **Giving In, Giving Up, Going Back, or Going On: Experiences of Unwanted Obesity**

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Current weight management strategies promote caloric reduction and increased activity, but have minimal long-term success. The purpose of this study was to explore the experience of weight management in obese adults using Glaserian grounded theory. According to the theory of integration (Hernandez, 1991), in chronic illness there are two competing selves which must be 'reconciled' for healthy living. In weight management, these are the obese (actual) self versus the normal weight (desired) self.

Participants were adults (4 males, 6 females) classified as obese according to body mass index (BMI  $\geq 30$ ). They were engaged in a 2-hour focus group discussion, using open-ended questions. Focus group audiotapes were transcribed verbatim and analyzed according to the tenets of Glaserian grounded theory.

Participants identified a complex set of interacting influences that predisposed them to ongoing obesity. Managing weight was an ongoing process of constant thinking about food and weight management, constant struggle to strike a nutritional balance, and interaction with and reaction to self, others, food, circumstances, and technology. Participants either acknowledged defeat (**giving in** to demands or **giving up** trying to succeed), retreat (**going back** to previous habits) or struggling to compete with weight-promoting influences and engaging in new weight-reduction strategies (**going on**).

The insights provided in this study may be helpful for other obese individuals contemplating or struggling with weight loss. The results can also be used to develop new weight management strategies or to strengthen existing interventions.

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### **Good, Bad and Not So Ugly: Doing Mixed Method Research**

Vicki Parker

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Michelle Giles

*University of New England*

This paper reports the experiences of a team of researchers undertaking mixed methods research within a Local Health District in NSW, Australia. We reflect on the benefits and challenges we experienced undertaking two studies, the first a study of readmission to ICU, and the second a study of the advanced practice role of Clinical Nurse Consultant.

In the first of our studies, mixed method research enabled us to use existing data and to work with clinicians from a position of shared knowledge and concerns about increasing numbers of patients being readmitted to ICU. Through examination of existing data bases we were able to connect our research with demonstrated need whilst at the same time building a platform for change and ongoing research. The information gleaned from quantitative analysis showed us where to go to and who to target in the qualitative component of our study.

In our study of Clinical Nurse Consultants, we examined how the role was enacted and how it was incorporated into service delivery models. We applied a concurrent data collection design using survey and focus groups. The data has provided a rich source of information through which we have explored diversity, associations and been able to link extent, scope and patterns to contextualised narrative of views and experiences.

Mixed method research has posed numerous challenges for us, including issues associated with increased complexity, larger teams with diverse skills, larger data sets and difficulties with time frames, workload and writing up.

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### **Grounded Theory Study of the Impact of Scholarship on Teaching and Learning**

Rhoberta Haley

*Azusa Pacific University School of Nursing*

Establishing a culture of scholarship at an institution with a strong teaching identity requires evidence that engaging in research has a significant impact on teaching and learning. A Grounded Theory study of the impact of faculty scholarship on teaching, student success, and campus ethos will be offered for discussion.

In an environment where there is increased pressure for faculty to publish and for institutions to enhance their academic reputation, institutions with a strong history and culture of teaching excellence and concern for student development struggle to find a creative balance between the demands of scholarship and teaching so that faculty time and energy is focused strategically on activities that produce student success.

Using a Grounded Theory approach, this research effort explored the impact of faculty scholarship on their teaching, relationships with students, service to the community, and professional effectiveness. Twenty-five faculty members who had published in a peer-reviewed venue within the last three years were interviewed. Transcripts were coded and analyzed using a constant comparative process. The major themes will be illustrated in a diagram containing antecedents, consequences, strategies, intervening conditions, and environmental supports.

Strategies are offered for institutions that desire to shape a campus culture that balances scholarship and teaching and promotes student success. With a focus on engaging students in faculty research, doing research with the community, and valuing the scholarship of teaching, faculty can be engaged in scholarship that benefits student learning.

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## Health and Wellness: What Adults with Intellectual and Developmental Disabilities Identify As Facilitators and Barriers

Patricia Cannistraci

*The Sage Colleges*

Multiple national initiatives have established a focus on improving health, promoting healthy aging and preventing further disability from chronic disease among adults with intellectual and developmental disabilities (I/DD). Despite the recognized importance of health promotion, increased health disparities exist among this population. The literature reveals a lower fitness level, poor nutrition, and a general sedentary lifestyle have increased risk for chronic conditions such as heart disease, diabetes, dental disease, and vision problems. Notably lacking in the literature is inquiry of what these individuals perceive as facilitators and barriers to health. This study listened to the voice of participants with I/DD in an effort to identify their reality of health, inform practice and society at large of this priority, and shape health policy.

This qualitative study explored facilitators and barriers to health and wellness among participants using Photovoice and photo elicitation methodologies. Photovoice has been used to gather data when conducting research with vulnerable or marginalized populations who often times are not able to find voice or are represented by proxy voice. In addition, perceptions of support staff – key community members who are charged with facilitating health and wellness for the individual they support, were gathered through a focus group meeting.

While facilitators and barriers were similar to those of the general populations, a crucial observation was that participants were able to generate the study data, thus changing how we come to know about health and wellness and challenging assumptions about the ability of participants to inform practice and policy.

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## Home Sharing For Adults with Intellectual Disabilities: A Qualitative Exploration

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Tim Stainton

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Carole Robinson

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Home sharing is the fastest growing residential option for adults with intellectual disabilities (ID) in British Columbia. Over half of individuals with ID receiving residential supports in B.C. live in home sharing situations. Home sharing is similar to adult foster care where adults with ID reside with a non-disabled individual or family and where the caregiver is paid for her/his caring labour. The goal of home sharing is to provide individualized support in a way that enhances quality of life and social inclusion by balancing independence and support. However, significant concerns exist regarding the lack of safeguards and standards, the potential for isolation of both adults with ID and caregivers, the potential for economic motivation on the part of caregivers and/or private agencies, and the potential risk to adults with ID because the model is being adopted so rapidly.

This qualitative study explored the experiences of individuals living in Home sharing living arrangements (individuals with intellectual disabilities N=22 and home share providers N=31) as well as key stakeholders' perspectives (family members N=12 and key informants N=9). Semi-structured interviews were conducted with 74 participants. Thematic analysis identified factors contributing to positive experiences of home sharing (e.g., the importance of relationships, transition planning, and teamwork) and identified factors that constrain and/or undermine home sharing (e.g., crisis planning, lack of supports, potential isolation, and system disconnection). Implications for supporting home share participants in creating structures and processes that enhance self-advocates' experiences of inclusion and citizenship are discussed.

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**Hope against Hope: Exploring the Hopes and Challenges of Rural Female Caregivers of Persons with Advanced Cancer**

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Wendy Duggleby

*University of Alberta*

Jeanette Eby

*McMaster University*

This study has explored the hopes and challenges of rural female family caregivers of persons with advanced cancer. Data collection began in January 2009 and was completed in March of 2012. 304 journal entries were collected from 23 participants, and most of these entries were written daily for a two week period. Participants had the option of typing, writing or voice-recording their entries. We used a narrative inquiry approach in the analysis of the journals.

The journal entries participants completed as part of the Living With Hope Program (LWHP) provided inside into their daily lived experience, and highlighted their emotional journey, the various challenges of caregiving, the way they employed self-care strategies and the various hopes they had and what

fostered their hope. This research contributes to the much-needed assessment of palliative/end-of-life caregiver interventions, specifically around interventions that impact hope and quality of life, and illustrates the value of a narrative approach to both research and practise. 'Hope against hope' calls for researchers, health professionals and other supports in P/EOL care to encourage self-care strategies, self-reflection and social support to enhance caregivers' hope and capacity to cope while caring for someone with a terminal illness.

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**“I don’t think it’s dangerous when it’s wine”: Danish Alcohol Culture from a Public Health Perspective**

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Tine Curtis

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Charlotte Delmar

*Aarhus University*

Alcohol consumption levels in Denmark are high with the risk of increased morbidity and mortality in the population. It is suggested that people’s views of ‘normal’ use of alcohol must be the platform for formulating effective alcohol education and prevention strategies. However little is known about the cultural norms for alcohol use.

The aim of this study was to examine the perceptions of the cultural norms for alcohol use amongst different age groups. Five focus group interviews were conducted with one group per the following age groups: 16-20; 21-34; 35-44; 45-64; and 65-82. The groups consisted of both men and women with five to six participants in each group (a total of 27).

The unifying theme of this research was Danish people’s acceptance and expectance of social drinking. Alcohol is widely accepted and associated with mutual expectations to drink, leading to identification of cultural influences and facilitation to drink. The social drinking context plays an important role in people’s perceptions of the normality of drinking. This includes the selection of particular beverages, and regularly leads to consumption above the recommended levels for low risk to health. This calls for public health attention that promotes low risk drinking in the social context, and aims to prevent and reduce serious alcohol related harm and health problems across the population.

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**“If we design it, they will come”: A Case Study Analysis of Community Participation in Community Health Centres (CHCs) in Ontario**

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A case study of four Community Health Centres (CHCs) in Ontario was conducted to examine how CHCs engage marginalized communities in local health system planning and decision-making for health services within their CHC; and to understand the organizational and community determinants that influence the process of community participation in CHC planning and decision-making for health services. 28 in-person key informant interviews with CHC staff across the four participating CHCs, and a document analysis of organization reports were conducted. There were similarities across the cases on perspectives of how participation approaches with marginalized communities should be designed and implemented. Participants described the importance of well-defined mechanisms to ensure that the strategies involve those in the community who are greatly affected by the delivery of health services. Emphasis is placed on participation that is inclusive and authentic. Authentic participation was described as *“participation that works for all parties involved (i.e., staff, healthcare providers, the public) and stimulates interest and investment in both the CHC and citizens, [and] requires rethinking the underlying roles of, and relationships between, CHC staff and citizens.”* Varying participation approaches were described across CHCs, which include participation in Community Advisory Councils (CACs), community consultations, community forums, focus groups, surveys, and community needs assessments. A common theme described as a challenge to participation was ensuring an inclusive participation strategy with “hard-to-reach” groups. Participants explained that the most affected individuals experience limited opportunities to participation resulting from isolation, lack of information, and language barriers. CHCs have been successful in encouraging participation with the community by the provision of childcare for parents and creating an open and informal environment for community dialogue.

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### **Immigrant Women’s Food Choices and Practices in Pregnancy: a Pilot Study**

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*University of Alberta*

Joan Forgeron

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In 2006, almost 20% of Edmonton's population identified themselves as foreign born, with large populations having Chinese, South Asian and Filipino origin. Maternity care nurses may face challenges in conveying information about optimum food choices because of language difficulties and differences in reproductive health and food practices. The purpose of this pilot project is to understand ethnocultural food and health practices and how these intersect in a particular social context of cultural adaptation and adjustment in order to improve the care-giving capacities of health practitioners. Our research question is: how do health beliefs and practices during reproduction of immigrant women affect their food choices? We are employing a case study design to allow for multiple means of data collection, data collection in different settings, and different units of analysis. The sources of evidence include: a scoping review of the literature, photovoice, and photo-assisted semi-structured interviews. Pregnant immigrant women (relocating within last 5 years) attending the perinatal clinic or staying in the women's unit of the host hospital are being recruited until data saturation. Each woman will be asked to tell their story through photos, to discuss whether food choices represented are typical or not, and what factors influence their choices. Interpreters are being used for consent and interview procedures. Data will be managed and analyzed using Atlas.ti software, drawing upon Miles and Huberman's 11-step analysis framework. In consultation with healthcare professionals, we will produce a culturally appropriate visual tool for informing immigrant women about healthy perinatal food choices.

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**Improving Stroke Recognition by Ambulance Services**

Julia Williams

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Rachael Fothergill

*London Ambulance Service NHS Trust*

Melanie Edwards

*London Ambulance Service NHS Trust*

Patrick Gompertz

*Barts and the London NHS Trust*

This study took a validated instrument for recognition of stroke in emergency departments (ROSIER) and trialled its use in the London Ambulance Service to see whether it could be utilised effectively in prehospital settings by ambulance staff. When used in emergency departments, it has been shown that the ROSIER (Recognition of Stroke in the Emergency Room) test increases recognition of posterior circulation stroke by 11% when compared with the FAST (Face, Arms, Speech, Time) test. The question is can this be mirrored in a prehospital setting?

Data collection occurred over 15 months and, prior to starting the trial, paramedics and emergency medical technicians were educated in the use of this assessment tool through face to face instruction

and supplementary use of an educational DVD which included: background information about stroke management; the use of the ROSIER; the trial protocol and paperwork.

The qualitative component of the study, through focus groups, explores the clinicians' experiences of using the ROSIER in practice, as well as evaluating their educational experiences while being trained to use the ROSIER.

The presentation focuses on two elements of the research: a) findings including emergent themes pertaining to: general public's expectation of paramedics in the diagnosis/treatment of stroke; ambulance clinicians' perspectives as to the ease of use of ROSIER; issues of ROSIER vs. FAST; future developments in prehospital management of stroke; b) methodological challenges of using focus groups with paramedics and technicians who are working shifts on operational response vehicles.

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### **Invisibility in the Role of Preceptor: A Qualitative Study among Public Health Nurses**

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Gerd Unstad Haaland

*Bergen University College*

Astrid Synnøve Litland

*Bergen University College*

The study aims to present a grounded theory of the role of public health nurses as student preceptors in Norway.

Preceptors' working environment, support and competence affect how they perform the preceptor role, are therefore important for developing students and can influence students' roles as students and future professionals. Previous research has focused on precepting student nurses and not so much on public health nurses or other postgraduate students. Knowledge in this field is therefore lacking.

We conducted 20 interviews in 2007–2010 with public health nurses in addition to a focus group in 2011 with four participants. We used classical grounded theory methods to gather and analyse data.

The preceptors were very concerned about invisibility and lack of recognition of the preceptor role. This main concern was resolved by the strategy of being obligated and included three patterns: expectant performance, ambivalent performance and reluctant performance, all with differing motivation for being obligated. All stakeholders involved in clinical practice seem to contribute to making the preceptors' role invisible and thereby contribute to the lack of recognition, support and reward, which again seem to self-reinforce invisibility.

The study highlights the obligation of public health nurses in precepting students and increases the understanding of the complexity of this role. Ensuring education of a high academic standard requires paying more attention to developing effective support for the people involved.

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### Keeping the Focus in Interdisciplinary Education: Sharing Experiences

Kevin Connaire

*St Francis Hospice*

Honor Nicholl

*School of Nursing and Midwifery, Trinity College*

Jayne Price

*Queen's University Belfast*

Catherine Tracey

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Helen Malone

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Anne Hayes

*School of Nursing and Midwifery, Trinity College*

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*School of Nursing and Midwifery, Trinity College*

Carmel Doyle

*School of Nursing and Midwifery, Trinity College*

Caring for children with life limiting illness and their families requires adherence to optimising clinical practice. In the Irish context, there has been significant interest in and demand for the provision of palliative care services for children with life limiting illness and their families. The DoHC (2005:40) acknowledged that there was need for further education and training for all professionals involved in caring for children with life limiting illness and their families. Internationally, education has been shown to be central to such development.

In response to this need, the School of Nursing and Midwifery, Trinity College Dublin designed, developed and delivered three stand-alone modules in children's palliative care. These modules are unique in that they are the first inter-disciplinary modules in children's palliative care introduced in Ireland. Various considerations were given to the design and development of the modules, in terms of content and teaching strategies. It is regarded by many that several third level programmes become a ritualised process of information delivery and may not be designed according to the principles of adult education. This challenge is further increased when interdisciplinary students with mixed abilities and varied experiences share the venues of discourse.

As part of the programme evaluation process, data were collected through focus group interviews with a variety of stakeholders involved in the project. These include the strategic advisory group of the project, course committee members, curriculum review group and course lecturers. The presentation will provide an overview of the experiences of a broad spectrum of disciplines involved from the time of the project inception to its final evaluation. In addition, consideration is given to the strengths and limitations of focus group interviews as a data collection approach in palliative care education.

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### **Knowledge Translation in Medical Education: Revelations from a Multi-Phase Research Project**

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*University of Toronto*

The study of knowledge translation has grown steadily over the past decade, in part as a response to a perceived gap between scientific research and clinical practice. Less attention, however, has been directed to understanding how empirical knowledge is utilized within health professional education systems.

This project sought to review the evidence for various educational approaches in medical education as well as explore how such knowledge informs existing curricula and educational practices. We employed a sequential mixed-methods approach consisting of three overlapping phases. The first phase involved a scoping review of the medical education research literature to map the sources and types of evidence

available for curriculum development, teaching and assessment approaches. The second phase involved content analysis of undergraduate course curricula documents at a Canadian Medical School. The third phase involved semi-structured interviews with medical faculty at the same institution to explore how they use evidence in their education practices.

Findings from phase 1 highlight key areas of focus within the medical education research literature. These findings also reveal that existing evidence is limited and more rigorous studies are needed to inform curriculum development, teaching and assessment activities. Findings from phase 2 suggest that only a small number of areas from the scoping review are explicitly integrated in the undergraduate curriculum. Results from phase three illustrate determinants of knowledge use among medical faculty and highlight challenges to knowledge translation efforts in the medical education system.

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### **Letting Go When Life Is Nearing Its End: The Final Stage of Transition**

Kevin Connaire

*St Francis Hospice*

Dying has been conceptualised within a variety of models, from a task based approach to living-dying interval approach. The uniqueness of individuals' dying trajectories requires carers to adapt to individuals' needs to support them as they reach their final stage of living. Little is known as to how patients address the final struggles they encounter in the last days of life and how nurses support them in this struggle. How they struggle, or become reconciled to the inevitability of death, is a personal and unique experience. What is absent at this crucial point in the caring relationship is how patients "actually" feel at this time. Additionally little is known as about how nurses caring for those patients address patients' needs at this time.

The aim of this presentation is to provide insights into how terminally ill patients address the struggles they face in the last few days of life.

This hermeneutic study involved interviewing patients who were being cared for in in-patient specialist palliative care units and specialist palliative care nurses who were caring for them. Analysis was guided by the work of Heidegger and Gadamer.

Findings indicate that patients encounter periods of disintegration of the self. Inner strength, legacy, remodelling and shielding provide the foundation for transition. Healing from wounded past life experiences influence the readiness and ability to reintegrate the self to a stage of progressing within the living – dying trajectory.

Patient attunement and therapeutic relationships are needed by staff in order to recognise the various stages of disintegration of self.

### Acknowledgement

The above findings are from a PhD study, supported by a Nursing and Midwifery Fellowship, Health Research Board, Dublin (2000- 2003).

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### **“Live Life to the Fullest” and Other Mantras: The Culture and Existence of Young Adults with Cancer**

Chad Hammond

*University of Saskatchewan*

Ulrich Teucher

*University of Saskatchewan*

Being diagnosed with cancer in young adulthood may come as a shock to some. This change of fate is often unexpected, due to prevailing cultural discourses (within both medicine and the public at large) about young adulthood as a time of relative health and productivity. Many of young adults' assumptions about their lives and worlds are put into question, leading to many forms of existential crisis. Despite some failure to account for their unexpected diagnosis, dominant cultural discourses are still engaged in the effort to make sense of life—sometimes they are reaffirmed, sometimes resisted. We sought to understand how cultural narratives surrounding young adulthood, and chronic illness, are engaged by young adult cancer patients. We interviewed and received written narratives from 20 young adults across Canada. Through critical phenomenology, we analyzed the narrative construction of their experiences. We paid particular attention to the existential issues raised within their narratives, as well as the cultural discourses that inform them (either as unsatisfactory points of departure or as existential footing). Some of the predominant existential issues were related to negotiating 'survivorship' identities, imagining possible work and home lives, and addressing the enduring mystery of future relapses. Participants responses to these existential issues often came out as mantras with both descriptive and prescriptive undertones, such as “cancer is a part of you, but you are not your cancer”, “live life to the fullest”, and “you have to remain positive”. In our presentation, we describe how these mantras and the issues they speak to are culturally scripted ways of interpreting the mundane, the adverse, and the sublime aspects of young adult life with cancer.

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### **Living with Bipolar Disorder: A Phenomenological Investigation**

Richard P. Freedberg

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Mary Lagerwey

*Western Michigan University*

The specific aims of this phenomenological study were to gain a broader understanding of the lived experience of adults with bipolar disorder and to explore how people diagnosed with bipolar disorder coped with life stressors and circumstances. Eight English-speaking people aged 18 or over who had

been diagnosed with bipolar disorder for at least one year participated in hour-long, semi-structured interviews. The interviews were recorded and transcribed. Four themes emerged: (a) diagnosis brings understanding accompanied by irrevocable change, (b) finding effective treatment is an interminable process, (c) bipolar disorder is the third partner in every relationship, and (d) caring for oneself is as important as receiving formal treatment.

Participants reported a wide variety of coping strategies. Cognitive means centered on self-monitoring of symptoms, managing the stigma of a bipolar diagnosis, and a conscious decision to care for oneself. The participants who were pregnant spoke of challenges of living without their medications, constantly balancing their needs, and seeking information on bipolar disorder and pregnancy. Allowing oneself to feel hope for the future, joy in caring for a pet or in service to others, or satisfaction being alone or with others reflected affective means of coping. Participants frequently mentioned activities that had spiritual meanings for them, such as music, journaling, listening to nature, and formal practices such as prayer.

The findings from this study point to the importance of assessment and nurturance of client self-care strategies by mental health care providers.

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### **Look for FACTS: A Pragmatic Approach to a Quick and Comprehensive Assessment of Rigor in Qualitative Inquiry**

#### **Fittingness, Auditability, Credibility, Trustworthiness and Saturation**

Mohamed El Hussein

*Mount Royal University*

Rigor in qualitative research is an issue of debate among nursing scholars and students. The proposed organizational framework (FACTS), assists students and scholars in evaluating and conducting research projects. For students evaluating qualitative articles can be a struggle as students often inter-mix quantitative evaluation techniques (critique) with qualitative approaches. Scholars conducting research need to be mindful about the different strategies utilized in qualitative research in ensuring the trustworthiness of their findings. Application of FACTS can facilitate and enhance this process. FACTS stand for: (1) Fittingness (also termed transferability) is the ability of the researcher to demonstrate that the findings have meaning to others in similar situations. Transferability is dependent on the degree of similarity between two contexts; (2) Auditability is the maintenance of a comprehensive record of all methodological decisions, such as a record of the sources of data, sampling, decisions, and analytical procedures and their implementation; (3) Credibility is the vivid and faithful the description of the phenomenon. A study is credible when it presents such a vivid and faithful description that people who had that experience would immediately recognize it as their own; (4) Trustworthiness refers to the quality of research report that is to the steps taken to ensure that the study procedures meet high standards and that you can trust the results and (5) Saturation refers to informational redundancy,

meaning that no new information is being obtained. This organizational framework, while deceptively simple, provides a powerful tool for novice and new researchers in developing strong foundations.

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### **Making Sense of Data: Ethnographic Fieldwork in Healthcare Organizations Located in Deprived Areas**

Christine Loignon

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Martin Fortin

*University of Sherbrooke*

Jeannie L. Haggerty

*McGill University*

Christophe Bedos

*McGill University*

David Barbeau

*CLSC Suburbs*

Thomas Gottin

*Université de Montréal*

Émilie Goulet

*University of Sherbrooke*

The aim of this presentation is to present results on the process and outcomes of an ethnographic study combining observations and interviews on the interactions between family physicians (FPs) and persons living in poverty. The objective of our study was twofold: 1) to explore factors contributing to positive interactions between FPs and patients living in poverty; and 2) to understand, from the patients' perspective, the perceived impact of such positive interactions. We conducted observations and dyadic interviews (32 semi-structured interviews) in four primary healthcare organizations in deprived metropolitan areas of Montreal, Canada, between 2009 and 2012. We coded and analyzed our data iteratively with NVivo, using an interpretive framework. Patient shadowing allowed us to grasp many nuances in how organizational structure and local initiatives influence the patient's experience of care. Our observations in the FPs' offices confirmed many common factors of the lived experience raised by FPs and patients in their narratives concerning positive healthcare interactions in a context of poverty. FPs used a socio-humanistic approach to care that was based on a collegial model of interprofessional relationships. Patients appreciated not only the socio-humanistic approach to care of FPs but also that their complaints were acknowledged and that the entire clinic was devoted to helping them develop resilience in dealing with multiple chronic illness conditions, poverty and difficulties in navigating the healthcare system. Our results will provide empirical data for developing patient-driven healthcare interventions to address the needs of people in poverty.

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## **Male Survivors' Perceptions of Post-Traumatic Stress Disorder Management Strategies in The South African Mining Sector**

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*University of South Africa*

Lindiwe Innocentia Zungu

*University of South Africa*

Ntambwe Gustav Malangu

*University of Limpopo, Garankuwa Campus*

Deep shaft mining is regarded as a high risk occupation with an increasing number of traumatic accidents. Though there are strategies for the management of post-traumatic stress disorders, little has been done to document the male survivors' perception of the treatment they receive from health practitioners during traumatic events.

An exploratory, descriptive and contextual study was conducted within the South African mining sector to explore and describe the survivors' perceptions of treatment strategies employed by health personnel in the management of PTSD resulting from mining accidents. The population comprised all men who were suffering from PTSD in the mines. A purposive sample of 30 men was selected and determined through saturation of data to participate in the study. In-depth individual unstructured interviews and field notes were used as methods of data collection. One question was asked during interviews: "What do think helped you recover from PTSD?" Communication skills were employed to facilitate the participation of men during interviews. Data were collected using a voice recorder, transcribed verbatim and analysed using Tesch's descriptive method of data analysis. Measures for ensuring trustworthiness were applied to verify the findings.

Three themes emerged during data analysis, namely: (1) perceived emphasis on physical versus psychological treatments, (2) perceived coping strategies used to deal with the trauma and lastly (3) the perceived effect of social support networks during trauma. Based on perceptions of participants, it became evident that PTSD management did not meet expectations. The integrated approach was recommended for future treatment of psychological and physical trauma among survivors of traumatic events in the mining sector.

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## **Meaning of Giving Informed Consent in Older Adults**

Herlinda Zamora

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According to a 2011 National Institutes of Health report on global health and aging, 524 million people are over 65; by 2050 it is projected that 1.5 billion persons will be over 65. Older adults ( $\geq 65$  years) are major health care consumers of surgical procedures. A 2006 survey in the United States reported that

approximately 65 million surgical procedures requiring informed consent were either ordered or provided annually. Recently, the push for “consumer engagement” and “consumer centered care” has resulted in some improvements in the informed consent process. In this drive for quality improvement, the voice of older adults regarding their informed consent experience is missing. The purpose of this case study was to explore an older adult’s experience of giving informed consent. Using a hermeneutic phenomenological approach, a case study was conducted to explore this experience. Data were collected in a one-to-one interview and field notes. This older adult described a personified account of “being in the world” of giving informed consent. Emerging themes include: receiving information, being informed, trust in health care providers, and being in control. These preliminary interpretations provide guidance for a further in-depth investigation of the meaning of giving informed consent. Ultimately, findings will help older adults make better decisions regarding their needs for surgical procedures, as well as, aid interprofessional health care providers, educators, researchers, and policy-makers to make recommendations and develop age-specific interventions to improve the informed consent process in these vulnerable health care consumers.

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### **Men’s Perceptions of Improving Couple Support in Endometriosis: The Role of Qualitative Research**

Lorraine Culley

*De Montfort University*

Nicky Hudson

*De Montfort University*

Elaine Denny

*Birmingham City University*

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Nick Raine-Fenning

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Endometriosis is a common gynaecological condition which has been shown to seriously restrict the physical and social functioning of women. Common symptoms include pelvic pain, fatigue, heavy periods, and a deep pain experienced during sexual intercourse. It is also associated with 40% of attendances at infertility clinics. Several studies have demonstrated the negative impact of endometriosis on women across a wide range of life domains, including work, finances and recreational activities. However, little is known about how the intimate partners of women experience living with this condition nor is there evidence of the kinds of support that might help couples in particular. This paper is drawn from an ESRC funded dyadic qualitative study of couples which aims to make recommendations for ways in which couples can be best supported through what is often a highly stressful long-term condition. The paper explores some of the methodological issues inherent in this project and discusses how male partners of women with endometriosis make sense of a gendered

condition which they cannot directly experience. It explores what challenges endometriosis makes to men's own quality of life; how they view the impact on their relationship with partners and what kinds of support they would find useful in negotiating life with endometriosis. The study provides some useful insights into how academics can work collaboratively with patient groups and healthcare providers to develop recommendations for healthcare interventions.

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### **Methodological Implications of Studying Migrant Philippine Educated Nurses working as Live-in Caregivers in Canada**

Bukola Salami

*University of Toronto*

Sioban Nelson

*University of Toronto*

The Live-in Caregiver Program is a Canadian temporary immigration program that allows qualified individuals to migrate to Canada to provide care to the elderly, children or the disabled, while living in the client's home. Live-in caregivers qualify to become permanent residents in Canada after a minimum of 3900 hours of work. This paper reports on the first data collection phase of a doctoral study that explores the experiences of internationally educated nurses who migrate to Ontario through the Live-in Caregiver Program. The study was primarily guided by the transnational feminist concept of Global Care Chain. Coined by Sociologist Arlie Hochschild, the concept of Global Care Chains illustrates personal links across the globe based on the paid and unpaid work of caring. Taking a single case study methodological approach, thirteen Philippine educated nurses who migrated to Ontario through the Live-in Caregiver Program were interviewed for this study. The majority of participants were temporary migrants in Canada who were seeking permanent resident status at the time of the interview. The process of data collection revealed the perceived vulnerability of this population due to their status as non-citizens and their responses evoked a new definition of reflexivity and positionality for the researcher as a Canadian educated African immigrant nurse conducting a research study on Philippine migrant workers. Methodological implications of conducting a study on migrant workers seeking citizenship status in Canada will be discussed as well as issues of reflexivity and positionality as an African immigrant crossing racial and cultural boundaries in the data collection process.

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### **Methodological Issues and Challenges Associated With Cross-Cultural and Cross-Language Qualitative Health Research**

Terry Cheng

*Princess Margaret Hospital, University Health Network*

Cross-cultural/language psychosocial oncology research is needed more than ever as we continue to face an increasingly diversified cancer population who identify English as their second language.

Traditionally, non-English speaking subjects are excluded from health and psychosocial research due to the high costs associated with interpreters, translation and the hiring of bilingual staff. As a result, their voices, perspectives, concerns and cancer survivorship experiences are under-represented in the literature. Although conducting cross-cultural/language research is rewarding, it introduces a host of methodology issues and challenges that could compromise the research process and quality of data. Language translation is not a simple linguistic exercise. It is a complex process that plays a major role in influencing the quality of the data and data analysis.

This presentation will highlight the methodological issues and challenges in handling Chinese-English translation and interpretation of data. As part of the thesis phenomenological study on breast cancer survivorship experience of Chinese women, a purposeful sample of 24 Chinese women was recruited, and audiotaped face-to-face semi-structured interviews were conducted in English or Mandarin by the researcher who is bilingual in both languages. Data analysis was carried out in both Chinese and English. An iterative process was carried out to identify the emerging themes.

Bilingual qualitative health researchers play a unique and invaluable role to accommodate the challenges inherent in cross-cultural research ensuring diversity of voices and experiences are heard and documented. The development of a culturally and language sensitive research environment is essential in promoting social inclusion and advocating for changes in health care practice, policy and education.

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### **Methods for Conducting Qualitative Synthesis: Aggregating, Integrating and Interpreting Islands of Exploratory Data**

Michael Saini

*University of Toronto*

Qualitative synthesis within the family of systematic reviews meets an urgent need to use knowledge derived from qualitative studies to inform practice, research and policy. Despite the contingent nature of evidence gleaned from synthesis of qualitative studies, systematic synthesis is an important technique and, used judiciously, can deepen our understanding of the contextual dimensions that emerge from qualitative research. This oral presentation will present an overview for planning, developing and implementing qualitative synthesis within existing protocols and guidelines for conducting systematic reviews. Using examples of published works, the presentation will explore methodological challenges, including: the philosophical tensions of integrating qualitative synthesis within the family of systematic reviews; the balance of comprehensive and iterative information retrieval strategies to locate and screen qualitative research; the use of appraisal tools to assess quality of qualitative studies; the various approaches to synthesize qualitative studies, including interpretive, integrated and aggregative; and the tensions between the generalizability and transferability of findings that emerge from qualitative synthesis.

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## Mexican-American Perceptions of the External Causes of Mental Distress

Iran Barrera

*The University of Texas-Pan American*

Celia H. Schulz

*The University of Texas-Pan American*

Stephanie Anita Rodriguez

*Petersburg Mental Health Services*

Crystal J. Gonzalez

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Celia A. Acosta

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This study reports a subset of data obtained from 82 interviews with Mexican-Americans about their perceptions of the causes of mental distress. Rigor and trustworthiness of data were insured by the use of multiple coders and categorizers, and bracketing, during the qualitative data analysis process. Data fell into three overarching categories: Internal Aspects; External Aspects; and How Mental Distress Develops. Data from the second overarching category, External Aspects, fell into eleven categories and are reported here: 1) Environment; 2) Emotional Experiences; 3) Family/Home; 4) People/Relationships; 5) Occupations; 6) Resources; 7) Life Attainment; 8) Life in General; 9) Social Institutions; 10) World Suffering; 11) Witchcraft. The results of this study have implications for mental health practitioners regarding clients' family problems, experiences of loss, and money problems, as well as implications for employers regarding stress experienced by their employees at work. Only one participant out of 82 identified witchcraft as an external cause of mental distress. This data can be used to inform mental health professionals about the external causes of mental distress as perceived by Mexican-Americans in South Texas, and can help form better partnerships between Mexican-American clients and their mental health professionals to assist in increasing mental health care utilization rates among Mexican-Americans. Discussion will also address the use of qualitative methods in this study.

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## Mixed Methods Data Collection Using iPads: Experiences from the Translating Emergency Knowledge for Kids (TREKK) Project

Lauren Albrecht

*University of Alberta*

Lisa Given

*Charles Sturt University*

Shannon Scott

*University of Alberta*

In Canada, the majority of children requiring emergency care are treated in general emergency departments (EDs). Evidence shows that up to 40% of children treated in general EDs do not receive

treatments for which clear evidence exists and up to 20% of these children receive a treatment that has been shown to provide no benefit or even causes harm. The Translating Emergency Knowledge for Kids (TREKK) project is aimed at ensuring the latest research in pediatric emergency medicine is applied in general EDs. In the first phase of TREKK, we have partnered with 35 general EDs across Canada to determine knowledge needs and preferences of ED healthcare providers and families seeking care. In this mixed methods study, healthcare professionals and parents seeking care for their children will complete electronic surveys via a custom iPad 'app.' SPSS will be used to analyze questionnaire data. Sites will also be purposively sampled to participate in qualitative data collection. The camera, video, notes, and voice memo iPad functions will be used to document the general ED experiences of both populations and serve as prompts during individual interviews, which will be analyzed thematically. The creation of the data collection tools, the electronic platform, and attending to research ethics boards/operational approval boards has been a complex and labour intensive processes. We believe novel technology increases participant engagement and enhances large scale data collection; however, in our experience, it was necessary to rethink traditional approaches to research coordination and administration. We intend to share 'lessons learned' from TREKK.

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### **Music and Emotional Well Being: An Anthropological Perspective on Qualitative Health Research**

Deirdre Zasorin-White

*University of Alberta*

In recent decades, studies have demonstrated the usefulness of the Arts within mental health care programs, especially among aboriginal populations (Cox et al. 2010, Ferrera 2004). By utilizing a model of inquiry demonstrated by Clandinin and others (Clandinin and Connelly 2000, Charron 2006), as well as qualitative methodologies including musical performance and lyrical analysis, I attempt to demonstrate the link between music making and emotional well being among urban indigenous youth in western North America. Through the words, images and music of eight different aboriginal research participants, a correlation between musical performance, emotional and social well being was revealed. In an effort to maintain the spirit of innovative qualitative research, the project was largely collaborative, with participants contributing their voices, music and lyrics via social media, audio recordings, videos and spoken interviews. Their stories, suggestions and questions were an integral part of the research process. Although my research was conducted from an anthropological perspective, similar projects have been successfully carried out by scholars interested in illness narratives (Hunter et al. 2011) and public health (Ferrera 2004). Data collection techniques from a variety of different fields, including anthropology and ethnomusicology, were deployed in this study. Through a qualitative and collaborative approach, I attempt to demonstrate the uses of both anthropology and the Arts within qualitative health research in order to discern how musical performance and expression may contribute to emotional well-being.

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### **“My Situation Wasn’t That Unique”: The Experience of Teens in Abusive Relationships**

Sharyl Toscano

*University of Alaska*

In this study, the researcher invited college freshman and sophomores with histories of high school dating violence to participate in a qualitative study about that experience (approved by IRB). Ten female participants were asked to recall their high school experience. The shared experience described by participants was that of being controlled. Control is established by creating a sense of responsibility and is maintained by angry outburst, threats to self, and guilt. Participants described an expectation of constant contact that included techno vigilance. In their stories, young women miss good and better times, hope for “the ideal romance”, and continue to care and have concern for their abuser who is described as “troubled. The experience of high school dating violence is replete with sexual pressure and/or rape. The experience follows and continues to the college setting. Restraining orders have the effect of ending the relationship for the duration of the order but contact is renewed once the order expires.

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### **Narrative Inquiry into Therapeutic Relationships: Deepening Practitioners’ Self-Reflective Practice**

Carrie Briscoe

*University of Waterloo*

Susan Arai

*University of Waterloo*

In health research, narrative is often used to understand experiences of trauma and illness. This presentation shares insight into use of narrative research in action to support health practitioners’ self-reflection and deepen application of theory in practice (praxis). In this study we explored use of narrative to deepen health practitioners’ understanding of their therapeutic relationships.

A self-reflective case review process was explored using observation notes, follow-up focus groups about the team’s experience of the process, and interviews with each case review leader. In this narrative exploration we storied practitioners’ original narratives of a therapeutic relationship they found challenging (the case), then explored how the team restoried that narrative in the case review process. This revealed how the team used current experience and theoretical knowledge rooted in medical, behavioural, and person-centred approaches to understand the case. A final restorying of the case offered the team new understandings using a lens of relational theory. This restorying highlighted relational qualities within the therapeutic relationship (connection, disconnection, impasse, authenticity) creating opportunity for further reflection.

In addition to offering further insight into therapeutic relationships practitioners formed with their clients, this process also shed light on and strengthened therapeutic relationships within the health care

team including feelings of trust, safety, support and mutuality, and willingness to be vulnerable and take risks. This study revealed the power of narrative methodology to support practitioners to explore the influence of theoretical perspectives in practice, and to strengthen connections with the people they serve and within the health care team.

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### **Navigating the Complex Ethical Dimensions of Qualitative Health Research as an Early Career Researcher and Mental Health Practitioner: Conversations with Women Living With an Eating Disorder**

Megan I. Jones

*University of British Columbia*

Kathleen M. Pye

*University of New Brunswick*

Research in the area of eating disorders remains largely dominated by quantitative approaches, limiting our understanding of women's lived experiences. Indeed, women's voices are often absent in the empirical literature. Qualitative research affords a deeper, contextualized understanding of the meanings women attribute to their experiences, and thus, may enhance empirical and clinical knowledge of women's health-related concerns. However, women with an eating disorder, like others struggling with secretive and stigmatized issues, are particularly vulnerable; the physical, cognitive, emotional, and social difficulties often experienced are well documented, yet less often discussed in the context of research methods. Arguably, explicit attention to the ethical issues inherent to qualitative research in this area is essential, particularly for mental health practitioners who, by virtue of their training, possess specialized skills that render them uniquely positioned to engage in qualitative research. These professionals are also faced with the task of reconciling the roles of care provider and researcher. In light of these challenges, this presentation aims to identify and explore a number of ethical issues relevant to qualitative research with women living with an eating disorder, and other vulnerable populations. Specifically, this presentation will: (1) outline ethical issues warranting consideration throughout the research process, with explicit attention to their relevance when working with women with eating disorders; (2) address these issues from the perspectives of early career researchers and mental health practitioners; and (3) discuss implications and resources for those engaging in qualitative research with vulnerable populations.

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### **Negotiating Intersections: Inter-Professional Practice in Rural Health Care Contexts**

Vicki Parker

*University of New England*

Rebecca Mitchell

*University of New England*

Karen McNeil

*University of New England*

Yvonne Ahrens

*University of New England*

Isabel Higgins

*University of New England*

Glenda Parmenter

*University of New England*

Penny Paliadelis

*University of New England*

Michelle Giles

*University of New England*

Health care in most contexts depends on teams of professionals with diverse skills working together synergistically to achieve optimal outcomes for patients and their families. The way in which interprofessional practice occurs in rural healthcare varies from that which occurs in metropolitan areas. This variation reflects the social, economic and geographic characteristics of rural communities. Further, rural workforce challenges and lack of access to resources and services are compounded by the difficulties associated with the intersection of speciality driven metropolitan models and the generalist models of care that are a feature of rural health care.

This study's aim was to examine how IPP happens in rural contexts, and to identify barriers, enablers and existing and potential models of IPP.

Interviews were conducted with health professionals (nurses, doctors and allied health) in a range of rural healthcare contexts (Hospitals, GP practices, Multi-Purpose Services and Community centres) in NSW, Australia. Interview data were supplemented with document review and review of communication systems.

Findings suggest that the nature of IPP in rural contexts is diverse and determined by a number of critical factors including rurality, connection to community, availability of staff, funding programs and specific interests and skills of staff. Rural IPP is characterised by a small number of professionals across few professions, focus on generalist practice and informal communication systems. IPP is growing in response to changes in government funding models and policy and through the establishment or strengthening of pivotal co-ordinating roles, with a clear mandate to involve other professionals and patients in decision making.

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### **Negotiating the *In-betweenness* of Dying at Home**

Lisa Seto Nielsen

*York University*

Jan Angus

*University of Toronto*

Denise Gastaldo

*University of Toronto*

Doris Howell

*University of Toronto, Princess Margaret Hospital*

Amna Husain

*University of Toronto*

Temmy Latner

*Centre for Palliative Care, Mount Sinai Hospital*

Death is often portrayed as a taboo topic within the Chinese community, and thus, the assumption is that dying at home may not be the preferred option. Beyond these stereotypical representations, little is known about what it is like for Chinese immigrants with terminal cancer to receive palliative home care. The purpose of this study was to examine how meanings of home condition negotiations of care between Chinese immigrants with terminal cancer receiving palliative home care, family caregivers, and home care providers. Postcolonial theory provided a critical lens for this focused ethnographic study of palliative home care for Chinese Canadian immigrants. The findings showed that the meaning of home was deeply altered as palliative home care occupied care recipients' and family caregivers' everyday lives. The home became the critical site (in-between, Third space) where meanings and subjectivities were continually translated, reconstituted, re-articulated, and enacted as new hybrid ways of caring, understanding, and living in the face of dying from cancer emerged. Three areas of concern that came up frequently amongst participants were: 1) discursive tensions in working with culture and caring for the individual; 2) dying at home: death as taboo; and 3) more than a language barrier. Home is a complex site where cultural "difference" becomes contextually salient when home care providers introduce palliative care. It was in the meeting, blending, clashing, and grappling of differences where participants had to negotiate and generate new, hybrid meanings and practices so that particularized, personal approaches to dying could be achieved.

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### **New Sites for Nursing Inquiry: Connecting Research and Pragmatic Relevance**

Sonia Udod

*University of Saskatchewan*

Louise Racine

*University of Saskatchewan*

Health research is now more directed at providing answers that will benefit the world of applied practice. Thorne (2008) argues that health research and nursing research in particular must find its own methodological approaches. Qualitative methods prove useful to push conceptual boundaries and build bridges to address real-life problems and address pragmatic issues arising from practice. Okhuysen and Bonardi (2011) argue that management issues often require explanations developed from a combination of perspectives to provide answers to complex questions. This presentation broadens the scope of theoretical contributions valuable to advancing nurse empowerment by examining the

complexities and processes of how power is exercised in nurse-manager relations. The authors argue that combining the organizational perspective (Conger and Kanungo, 1988; Kanter, 1993) and the critical social perspective enhances the explanatory power of designing more effective empowerment strategies for nurses. The authors report that the inquiry and methodology offer a critical juncture in advancing nurse empowerment by examining taken-for-granted practices; exploring resistance and creating a space for possible change by allowing nurses to (de)problematize managerial practices. This study brings innovative knowledge to nurse empowerment by revealing ways managers can engage with staff, provide opportunities for nurses to contribute to and influence organizational directives, and provide alternate and more productive way to improve patient care. The authors have taken up the challenge to advance new insights for previously unexplained phenomena surrounding nurse empowerment toward the development of nursing science.

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### **Nurses' Communicative Work at End-of-Life in Intensive Care Units**

Cynthia Peden-McAlpine

*University of Minnesota*

Joan Liaschenko

*University of Minnesota*

In spite of the amount of attention and funding spent on research of end-of-life (EoL) care, dying continues to evoke conflict, misunderstanding, and emotional turmoil. Much of the research on communication at EoL has focused on the decision-maker and diagnostic and prognostic information. In contrast, this paper reports on a study which examined communication as speech acts, that is, what is intended or gets done by speech and communication. A self-selected group of 18 nurses from two intensive care units (ICUs) were interviewed about the communicative work they did with families and staff to arrive at consensus regarding the shift from aggressive to comfort care. The language nurses use at this time is intended to accomplish three aims, which, in their view, improve EoL care. These are: creating a story to make sense of the situation and to direct the course of care; distributing responsibility for the death; and prescribing and evaluating actions. Creating a story consists of constructing the body, knowing the patient, and experiencing an ending. In term of distributing responsibility, previous research demonstrated that no one wants responsibility for the death – not physicians, nurses, or family members. Nurses' language is aimed at distributing responsibility so that family members do not feel as if they've caused the death. Lastly, communication prescribes and evaluates actions. Because this study moves beyond who is the decision-maker and what diagnostic and prognostic information is conveyed to what nurses' speech actually does, it offers approaches to study communicative work at the end-of-life.

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### **Oil on the Water: Smoothing the Journey of Palliation through the Use of Complementary Therapies**

Kevin Connaire

*St Francis Hospice*

Deirdre Ruane

*St Francis Hospice*

There is increasing incidence in the usage of Complementary Therapies in the management of patients with cancer and those receiving palliative care. Psychological, biological and social functions are frequently threatened following the diagnosis of a malignant condition and throughout the illness progression. Key symptoms for which complementary therapies are utilised include pain, anxiety, fatigue and depression. While the empirical literature to date has focused on the usage of various complementary therapies, there is limited evidence, within the Irish context, of the impact of those therapies on individuals with a cancer diagnosis receiving complementary therapy for the first time in specialist palliative care services.

The aim of the study was evaluate the benefits of receiving reflexology, massage, aromatherapy massage or reiki in patients with a life limiting illness in a specialist palliative care service. A longitudinal, descriptive qualitative design, involving thirty patients with a diagnosis of a malignant condition, was used. Interviews were conducted prior to the first complementary therapy treatment, following the third treatment and on completion of the final complementary therapy treatment. Conventional Content analysis guided the analysis process.

Findings suggest that participants had a desire to experience an improvement in a range of specific symptoms, which varied according to diagnosis. Some respondents expressed no expectations from their proposed treatment. An improvement emerged within specific symptoms in addition to enhanced therapeutic relationships and personal contentment.

Participants experienced renewed energy levels, enhanced self-perception with specific life goals, and reduced intensity of symptoms.

Physical, emotional and psychological benefits emerge early in receiving complementary therapies. These continue to improve throughout the course of treatment, when used in an integrated way with ongoing palliative treatment modalities. Complementary therapists and health care professionals need to be aware of patient educational needs concerning complementary therapy prior to commencing complementary therapies and educate patients accordingly. Further research is needed to explore the impact of additional complementary therapies not included in this study.

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### **Optimizing Hospital and Community-based Maternity Care for Immigrant and Minority Women in Alberta**

Gina Higginbottom

*University of Alberta*

Beverley A. O'Brien

*University of Alberta*

Zubia Mumtaz

*University of Alberta*

Sophie Yohani

*University of Alberta*

Yvonne Chiu

*Multicultural Health Brokers Co-operative*

Philomina Okeke-Ihejirika

*University of Alberta*

Elham Ahmadi

*University of Alberta*

Patricia Paton

*Alberta Health Services*

Jalal Safipour

*University of Alberta*

Although evidence suggests that immigrant women have difficulty utilizing maternity care services, little knowledge exists on how factors such as ethnic group, English-language skills, cultural norms, or pre-migration histories intersect and influence maternal outcomes. This three-year interdisciplinary project aims to increase understanding of how maternity services can better enable immigrant/minority women to have positive maternity experiences in urban and rural Alberta. A mixed-methods approach is being undertaken. Phase one incorporates secondary analysis of Canadian Maternity Experiences Survey (2009) data, related to women's views regarding quality of maternity services. Phase two is a focused ethnography using in-depth interviews and focus groups with immigrant women, healthcare professionals, policy makers, immigrant advocates and community representatives in Edmonton (n=44 completed) and Brooks (n=31). Qualitative data is being managed, classified and ordered with ATLAS.ti software and using Roper and Shapira's ethnographic analysis framework. A meta-ethnography using Noblit & Hare's approach forms phase three, and a knowledge translation program comprises phase four. Interim findings for data collected in Edmonton show that immigrant women participants are generally satisfied with medical aspects of their maternity care, but lack of antenatal and postpartum social supports tends to negatively shape their experiences. Communication difficulties were frequently mentioned by healthcare professionals, although racial profiling and stereotyping were also self-reported. Many of the resettlement issues noted by social services providers intersect to produce negative maternal outcomes. For optimal maternal health of immigrant women, a holistic approach is required with targeted interventions involving input from healthcare professionals, social service providers and immigrant communities.

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### **Palliative Care and the Heart Failure Team: Methodological Practice and Preliminary Findings**

Allan McDougall

*Western University*

Lorelei Lingard

*Western University*

Valerie Schulz

*Western University*

Joshua Shadd

*Western University*

J. Malcolm Arnold

*Western University*

Denise Marshall

*McMaster University*

Patricia Strachan

*McMaster University*

Glendon Tait

*Dalhousie University*

Gil Kimel

*University of British Columbia*

This presentation will discuss a methodological approach and present preliminary results from a patient-centered study exploring health care teams. Recent guidelines and consensus panels in the cardiology community advocate provision of palliative care concurrent with congestive heart failure (CHF) treatment. However, this emerging call for palliative care integration is based on research evidence derived from the study of individual patients and individual providers – their needs, preferences, attitudes and knowledge. Such work is insufficient to inform the development of educational and practice interventions that must be enacted not by isolated individuals but by members of a complex and distributed CHF care team that includes the patient with CHF and their primary care and heart specialist physicians, nurses, social workers, homecare workers and family caregivers. In order to inform integration efforts, we require research into the experiences and expectations of the CHF care team.

An approach to gathering qualitative data from across a distributed healthcare team was piloted using an innovative sampling strategy beginning with index patients and then sampling out. Patients with congestive heart failure were interviewed and asked to identify key members of their care team. These members, including family caregivers, heart specialists and general practitioners, were also interviewed regarding the index patient's care. Using a constructivist grounded theory approach, transcripts are being analyzed to explore patterns in terms of attitudes, expectations, and current practices.

11 team sampling units have been assembled. The team sampling units provide insight into the diverging and converging viewpoints of each of these patient care stakeholders around the issues of CHF care and palliative care integration. Role clarification and conflicting assumptions are emerging as salient. The team sampling unit is emerging as an effective, ethical and feasible method for accessing insights from across distributed healthcare team.

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## Parental Recognition of Pre-adolescent Overweight and Obesity

Jennifer Laurent

*University of Vermont*

**Background:** Approximately 75% of parents are unaware of their child's overweight or obesity. This study examined how parents become aware of their pre-adolescent's overweight/obesity and describes factors involved in acquiring this knowledge.

**Methods:** 17 parents of 9-14 year olds were interviewed. Data were generated and analyzed from the question, "How did you come to realize your child was overweight?". Additional open-ended supplementary questions were tailored to the response of the parent to support or explain evolving concepts, themes, and relationships, and to provide maximum density and variation in participant's responses. Strauss and Corbin's model of grounded theory guided data collection and analysis.

**Results:** 5 central themes emerged. **Predisposition:** Most parents felt there was some type of predisposition for their pre-adolescent's obesity. **Husky-build:** Parents avoided using the words overweight, obese, or fat to describe their pre-adolescent. **Compared to others:** Parents described how they compare their overweight preadolescent to others in terms of shape, eating, and exercise. **Healthcare Provider:** The role of the healthcare provider played a pivotal role in the awareness process. **Parental buy-in:** Through the integration and culmination of the previous 4 themes a tipping point was reached where parents achieved recognition of their pre-adolescent as overweight/obese.

**Limitations:** Retrospective study of parents, predominantly mothers, in a select region of the Northeast U.S.

**Conclusions:** This study highlights the complexity and multiple factors involved in the awareness process of parents with overweight/obese pre-adolescent and the pivotal role the healthcare provider can play in helping parents achieve this recognition.

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## Participatory Research with Street Involved Youth: Improving Access to Emergency Department Services

David Nicholas

*University of Calgary*

Amanda Newton

*University of Alberta*

Margaret deJong-Berg

*Alberta Health Services*

Faye Hamilton

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Peter Smyth

*Children's Services, Alberta*

Avery Calhoun

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Kathryn Dong

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Anne Marie McLaughlin

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Janki Shankar

*University of Calgary*

Christopher Kilmer

*University of Calgary*

This participatory, qualitative research examined Street Involved (SI) youths' experiences and needs related to Emergency Department (ED) Health Care services, and developed recommendations for optimizing accessibility, responsiveness and impact in collaboration with SI youth through the use of a Delphi Consultation. A participatory approach was preferred as the literature reported a disconnection between SI youths' experiences and values relative to those of "experts" who conduct research and provide health care. Prior to developing an integrated, inter-professional intervention, health and community professionals came together with SI youth to understand their experiences and needs related to health and ED use, relative to their health needs. The participatory study occurred in three phases: 1) engagement of SI youth, 2) focus groups with SI youth and service providers exploring existing needs, services and gaps, and finally 3) a Delphi consultation involving SI youth, ED and community services providers, and policy personnel.

Delphi consultation is a form of structured communication had with knowledgeable individuals, sometimes referred to as an "expert panel". Our participatory Delphi brought together experts including those "street involved youth", the focus of the research, in order to expand and translate research results into action plans regarding resource needs, gaps and strategies to address emergency care and health needs of SI youth. This presentation reports the findings of this research study along with a discussion of the processes and pitfalls of the participatory research design.

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### **Patient Centred Care: Involving Parents/Carers and Children in Developing Healthcare Interventions**

Lorraine Culley

*De Montfort University*

Monica Lakhanpaul

*UCL Institute of Child Health*

Deborah Bird

*University of Leicester*

Nicky Hudson

*De Montfort University*

Mark Johnson

*De Montfort University*

Patient centred care, patient choice and shared decision-making are three important concepts at the heart of government policy discourse in the UK. However, the extent to which such concepts are translated into healthcare provision for most citizens is debatable. The gap between rhetoric and reality is most stark in the case of minority ethnic communities, where there is considerable research evidence to suggest that marginalised communities have greater healthcare needs, but often receive inferior care. This paper discusses the role that qualitative health research can play in bringing the voices of communities, families and children into service design. It reports on the challenges and successes of developing interventions in partnership with British South Asian communities, with the aim of to helping families and healthcare providers to improve the management of asthma in South Asian children. This research project, funded by the UK National Institute for Health Research programme used key informant interviews, community focus groups, in depth qualitative interviews and deliberative workshops with parents/carers and children to explore how asthma was perceived in South Asian families; how asthma care for children was currently delivered and what parents, carers and children with asthma wanted from their healthcare providers. The data was used to develop a health interventions framework for asthma management in children, with prototypes which will be trialled with the UK National Health Service.

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**Peer Support and Mobile Phone among Refugee Women Living in Melbourne, Australia**

Pranee Liamputtong

*La Trobe University*

Dennis E. Wollersheim

*La Trobe University*

Lee C. Koh

*La Trobe University*

Rae Walker

*La Trobe University*

Newly arrived refugee women face cultural displacement, social isolation and a sense of ambivalence about their future. In the local Melbourne community, refugee women have been identified to be at particularly high risk of developing mental health problems such as anxiety, depression and post-traumatic stress disorder. Many of these problems can be alleviated through social support and the strengthening of community social capital. Support strategies that enhance social capital can increase personal, family and community 'capacity to deal with challenges and issues to find local solutions to local problems'. This paper discusses a current research exploring how mobile phone-enhanced peer support could improve the psychosocial health of refugee women and generate increased social capital by ameliorating isolation and using peer resources to resolve settlement issues. A mobile phone peer support program was implemented in which a total of 111 women from three communities (Sudanese, Burmese and Afghan) received peer support training and mobile phones which allowed free unlimited

intra-group calls and calls to selected local and overseas numbers. At the end of our program, we conducted focus group discussions with all groups. The study systematised the 'help from friends' concept by creating a timely, structured, easily accessible advice and support system among the refugees themselves. It appears that the program facilitates access to two useful resources: information and support.

We suggest that a mobile phone-enhanced peer support network could have a direct positive health effect on participants' lives and, indirectly, the lives of the people around them.

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### **“People Take Their Lead from What You Say and How You Are”: The Ethics of Rapport Between Queer Patients and Their Physicians**

Erin Fredericks

*Dalhousie University*

Ami Harbin

*Oakland University*

Health care policy increasingly views the patient-physician relationship as a collaborative partnership, which requires patient and physician to communicate and build rapport. Cultural competency training complicates this relationship by requiring physicians learn to interact with diverse patients. Where quality care requires collaboration, health care providers can be seen as having responsibilities to build rapport with their patients. Yet, in the context of these trends and ongoing heterosexism, rapport building between physicians and queer patients can be a complicated process, and one for which neither physicians nor patients are well-prepared. We draw on a sub-section of the results of an interdisciplinary feminist qualitative study to examine the ethics of rapport building. Through iterative, thematic analysis of interviews with 19 self-identified queer women and 12 family physicians in Nova Scotia, we found that physicians' approaches to building rapport often distanced queer women through exoticization, appropriation, and intellectualization. Other approaches required patients to do the work of building rapport, placing the onus on queer women to smooth encounters by being easygoing, funny, and matter of fact. Some women's positions as marginalized because of gender, sexuality, and class characteristics meant that they could not meet expected standards of 'likeability.' We describe select, promising examples of rapport building, where we see physicians and patients revealing vulnerabilities, allowing for conflicts, and engaging in conversation across (and sometimes directly about) difference. We suggest future directions for the ethics of rapport building with queer patients, which will become more relevant as health care becomes increasingly collaborative.

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### **Perspectives of Parenting on a Low Income in Toronto: The Voices of Parents, Public Health Home Visitors, and the Public At Large**

Dia Mamatis

*Toronto Public Health*  
Rita Paul Sen Gupta  
*Toronto Public Health*

Child and family poverty is a significant issue across Canada. There has been a call for more exploration of the lived experiences of low income parents to increase public understanding of how poverty affects their lives and inform action to improve their health and well-being. This presentation shares the findings of the Perspectives of Parenting on a Low Income in Toronto mixed methods study which explored the realities of parenting and promoting children's health and development in the context of poverty from three perspectives. Thirteen low income parents with young children and 16 public health home visiting staff were interviewed. An adaptation of photovoice was also used to bring parents' lived experiences to life. A telephone survey of 1000 Toronto residents examined public views on parenting on a low income and strategies that could improve the lives of low income families.

The unique insights of public health staff and parents' compelling stories and photos conveyed the impact of poverty on every aspect of families' lives. Parents' limited capacity to access food, safe affordable housing, programs and services, and education and employment were underscored. Parents and public health staff offered concrete solutions for increasing access to higher incomes and other key determinants of health. Toronto residents believe child poverty reduction to be a priority and were supportive of many of the suggested actions, even if tax increases were required. The findings are being used to support program, advocacy, and policy initiatives to alleviate the impact of poverty on parents and children.

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### **Photovoice Innovation for Engaging Aboriginal Children and Youth in Health Research**

Nancy L. Young  
*Laurentian University*  
Mary Jo Wabano  
*Nahndahweh Tchigehgamig Health Centre, Wikwemikong Unceded Indian Reserve*  
Tricia A. Burke  
*Laurentian University*  
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*Nahndahweh Tchigehgamig Health Centre*  
Stephen Ritchie  
*Laurentian University*

Children and youth comprise 40% of the Canadian Aboriginal population and are at risk for poor health outcomes. There is a need for evidence to guide health care delivery in this population. We sought to develop innovative research methods to capture the perspectives of Aboriginal children and youth, related to health and well-being.

We organized a series of 6 full-day focus groups with Aboriginal children and youth living on-reserve. The morning included: cultural practices, teachings from an Elder; and bicycling and photography in the community. This generated material for the afternoon photovoice session during which the children and youth discussed their photos and described how each related to health in the context of their community.

The participants ranged in age from 8.2 to 17.7 years. The role of Elders was critically important in setting the stage culturally. Bicycling enabled the participants to showcase their community and build relationships with the researchers. Using digital cameras to capture still photos kept the focus of the bike trip on health and well-being. The use of a slide show (in which the participants' favorite photos were displayed in random order) was effective in engaging each participant in presenting their ideas with pride as their photos appeared on the big screen.

The integration of bicycling with photovoice methods was innovative and extremely valuable in engaging the Aboriginal children and youth over a 6 hour period. This resulted in a comprehensive picture of health and well-being from a unique perspective.

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### **Post-Natal Women's Handling the First Period At Home with a Newborn: a Focus Group Study**

Esther Hjälmhult

*Bergen University College*

Kirsten Lomborg

*Bergen University College*

*Aarhus University*

The article aims to present a theoretical account of mothers' first period at home with their newborn.

Mothers' well-being affects their babies and is therefore an important priority for public health. Early discharge after childbirth is common in many countries. In Norway, this has been practised for 5–10 years but without any distinct agreement between maternity hospitals and the community health services. Knowledge is lacking in how mothers deal with the first period at home with the baby.

Seven focus group discussions were conducted with 26 mothers who had babies 1.5–3 months old. The grounded theory method was used to gather and analyse data.

The mothers were strongly concerned about preserving their control and integrity in the new situation. This main concern was resolved by the strategy of prioritizing newborn care. The strategy encompassed a process of developing competence as a mother, changing focus in relationships, stretching to the critical level and seeking recognition. These parallel processes were interrelated, sometimes mutually supportive and sometimes conflicting. When conflicts occurred, prioritizing newborn care guided

mothers in finding solutions. Breaches of the implied conditions in health care tended to increase mothers' level of strain and uncertainty and to influence their efficacy in breastfeeding the baby.

The idea that giving birth is a simple and normal situation may obscure the importance of seamless health care and the need for professional support and information.

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### **Potential Interventions to Enhance Adherence to Asthma Medication**

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Mark W. Aulls

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Simon L. Bacon

*Concordia University*

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Asthma is a chronic respiratory disorder whose treatment relies upon daily medication (inhaled corticosteroid) adherence and avoiding asthma triggers (e.g., smoke). Although the benefits of medication have been demonstrated, research shows that adherence is low in asthmatics. This study qualitatively explored patients', physicians' and allied health professionals' (AHP) perspectives concerning the design of an intervention aimed at increasing patient motivation to adhere to asthma medication (i.e., motivational interviewing). We interviewed 38 participants (n=13 asthma patients, n=13 respiratory physicians, and n=12 AHP's [e.g., nurses]) who discussed their perspectives concerning 'improving adherence to asthma treatment' during focus groups. Interviews were qualitatively analysed according to standard inductive procedures (Corbin & Strauss, 2008). Patients, physicians, and AHP's agreed that the intervention should be patient-tailored. Physicians and AHP's reported that the intervention should be led by physicians and supported by AHP's, though patients reported that the ideal provider could be any trusted health professional. Finally, physicians and AHP's agreed that the main goal of the intervention should be patient education, whereas patients and AHP's reported that it should provide education strategies for self-management. Results indicate that patients, physicians, and AHP's have different views about the ideal design of an intervention aimed at increasing patient motivation to adhere to asthma medication. Overall, findings suggest that it should be patient-tailored, focus on education providing self-management strategies, and could be delivered by any qualified health professional. Future studies are needed to assess the efficacy of such an intervention on improving asthma medication adherence.

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## **“Prisoner”, “Refugee” or “Settler”: Finding a Home in Residential Care Settings for Older People**

Adeline Cooney

*National University of Ireland, Galway*

This grounded theory study involved interviewing residents (n = 61) living in different types of residential care settings (n = 7) in Ireland. It was found that residents attempt to create a home in the residential setting. Some succeed in this task but others do not. This paper will focus specifically on what supports or hinders older people in finding “home”. ‘Creating a home’ was conceptualised as the core category and comprised of four properties: ‘continuity’, ‘belonging’, ‘preserving personal identity’ and ‘being active and working’. Factors that support (or constrain) older people in finding a home include the physical environment of the setting but also the social environment. Feelings of warmth and ease were associated with homeliness. Feeling part of the group promoted a sense of belonging. Staff attitudes and approach to care delivery were powerful determinants of residents’ experience. The individual’s expectations, past experience and involvement in the move coloured their experience of living there and determined the ease with which they settled. The paper will present the theory of ‘creating a home in residential settings and explore its implications for care.

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## **Qualitative Research and Whole Person Care: New Frontiers or Old Boundaries?**

Steven Jordan

*McGill University*

Thomas Hutchison

*McGill University*

This paper focuses on recent developments in whole person care that are currently being explored by a multi-disciplinary team of researchers at McGill University. While the paper will map out the history, aims/objectives, principles, impacts and current trajectory of what is now known as ‘Programs in Whole Person Care,’ it will primarily focus on questions concerning how to research this relatively new and emerging area of health care using qualitative methodologies.

In this respect it will have three aims. First, it will briefly outline the underlying philosophy and principles driving whole person care and what it considers to be its respective areas of interest within health care contexts. Second, the paper will then identify the different theoretical trajectories currently being explored under the auspices of whole person care and how these might connect with existing qualitative methodologies. Third, consideration will be given to how the concept and practice of whole person care might represent not only a new paradigm for 21st century health care practices, but might also be generative of new types of qualitative methodology/methods for researching health care settings.

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## **Rapid Malaria Diagnosis in Ghana: Implementing Policies, and Navigating Technology at the Point of Care**

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Daniel Ansong

*Komfo Anokye Teaching Hospital*

*Kwame Nkrumah University of Science and Technology*

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Stephanie K. Yanow

*University of Alberta*

Dev Menon

*University of Alberta*

Ghana's national malaria control policies recommend testing before treating all suspected malaria patients above five years of age. Rapid diagnostic tests (RDTs) allow for quick and reliable diagnosis of malaria in peripheral facilities with limited laboratory capacity, without having to rely exclusively on clinical diagnosis. Implementing national health policies in limited-resource settings can be challenging for frontline health services workers. Such challenges may be amplified where implementation involves the uptake of new technology, such as RDTs. Studies reveal variable extents to which test results are applied to clinical decision-making for suspected malaria cases across sub-Saharan Africa. Little is known about health workers' strategies for integrating RDT-use with fever case management in resource-constrained environments. A focused ethnography was carried out within a peri-urban district in Ghana's Ashanti Region, 1) to examine national guideline adherence among health workers performing rapid malaria diagnosis; 2) to investigate health workers' strategies for point-of-care malaria testing with RDTs; and 3) to understand how health workers integrate policy with practice amidst limited resources. This study involved district healthcare providers in direct observations, interviews and focus group discussions on rapid diagnostic testing for malaria. This paper presents early findings on how health workers in this study integrate RDT-use and applied policies for rapid malaria testing in their facilities. Lessons drawn will be useful for informing strategies to optimize the uptake of rapid malaria testing and similar point-of-care diagnostic technologies in developing country health settings.

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## **Reciprocity, Shared Leadership, and Complementarity: The Keys to Increasing Organizational Health Promotion Capacity**

Paula Bush

*McGill University*

Enrique García Bengoechea

*McGill University*

Sharon Parry

*YMCA Pointe Saint-Charles*

North American adolescents are not meeting physical activity (PA) guidelines for health. Few PA intervention studies focus on factors contributing to the capacity of organizations to deliver and sustain popular PA promotion programs for teenagers. To build on a YMCA's capacities to promote PA to teenagers, the researcher engaged in participatory research with the YMCA. Together, they conducted a mixed methods evaluation of the teen program to inform YMCA programming decisions.

For this three year case study, to understand the partnership characteristics and processes contributing to sustainable health promotion capacity changes at the YMCA, the researcher conducted thematic analysis of data, including email, meetings and interview transcriptions, and field notes.

Findings reveal the researcher and YMCA employees developed a relationship of reciprocal trust, support, and respect. This reciprocity, coupled with a shared leadership process, whereby the researcher would alternate between responding to YMCA partners' perceived needs and guiding partners beyond those needs, contributed to the researcher and YMCA merging their complementary objectives, knowledge, statuses, and skills to generate an inclusive vision, rationale, and description of the teen program. This inclusive perspective provided YMCA partners with insights, reminders, and validation, which in turn contributed to program evaluation and practice changes they are sustaining and transferring to other sectors, namely evaluation competencies (e.g., research methods), health promotion capacities and competencies (e.g. knowledge and use of social marketing strategies).

Lessons learned from this study are transferable to other partnerships striving to increase adolescent PA participation as well as general organizational health promotion capacities.

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### **Reducing Healthcare-Associated Infections in the Vancouver Metropolitan Area**

Daniyal Zuberi

*University of Toronto*

Healthcare-associated infections (HAIs) have become a leading cause of death of Canadians, and trends suggest that the HAI threat to patient safety will likely become more severe. Treating HAIs requires substantial healthcare expenditures, resources that could be more effectively spent on prevention.

The research identifies structural barriers to improving infection control practices in acute care facilities in Vancouver area hospitals based on interviews with 38 infection control experts and other stakeholders, including physicians and nurses. The findings highlight several important ongoing campaigns as well as important barriers to improving infection control. The data also point to staffing shortages among health care staff are described as a barrier to improving infection control. In addition, lower-status employees in a hospital face challenges monitoring or encouraging compliance with

infection control protocols of other healthcare staff with higher status in the institution. Another structural challenge is addressing the physical layout of many hospitals in terms of infection control. With an insufficient number of private rooms, in which to isolate infected patients, patients with different antibiotic resistant organisms are cohorted together. Respondents also describe perceived and actual financial obstacles to infection control compliance. Even when the efforts of infection control programs from frontline workers can be clearly linked causally to declines in infection rates, there is a perception that senior healthcare executives remain reluctant to utilize cost-savings to invest in further infection control initiatives. Improving infection control requires a focus on structural issues in the healthcare system to identify barriers to reduce healthcare-associated infection rates.

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### **Reframing Self-Management as a Complex Social Process: Disadvantaged Women's Understandings**

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Sue Mills

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Self-management is a term that is widely adopted in policy, practice and research related to chronic conditions. Self-management refers to the behaviours individuals engage in to manage their symptoms, treatments and the impacts of living with long-term illnesses. Disadvantaged women have higher prevalence rates for many chronic conditions, experience greater barriers to managing them, experience worse health outcomes, and higher rates of multimorbidities, yet, to date; we do not know how these groups of women understand self-management. This knowledge is essential for developing and implementing self-management support services that are relevant and appropriate for this population. To address this gap, we interviewed 22 women (ethnic minorities, single mothers and seniors) and used constructionist grounded theory methods and an intersectional lens to analyze their understandings of self-management in the context of daily life. In contrast to the emphasis on 'self' in current self-management support initiatives, our findings suggest that women's understandings of self-management are embedded in complex social processes about health and social services, addiction, food security, social inclusion, stable housing and poverty. Self-management is also about women's sense of agency in being able to negotiating these social processes by adopting particular attitudes (e.g. being in control and being independent). If we hope to make meaningful progress in supporting self-management behaviours and improving chronic conditions outcomes for disadvantaged women, current approaches must adopt strategies for addressing social processes through multi-level interventions.

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## Releasing Time to Care™ in Saskatchewan: Helping Hospital Units Organize for Quality

Jessica Hamilton

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*Saskatchewan Health Quality Council*

Ross Baker

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Releasing Time to Care: The Productive Ward™ (RTC) is a nurse led approach designed to eliminate waste and support quality and safety improvements. Using a mixed-method approach we are evaluating RTC concurrently with its implementation on acute care units in Saskatchewan, Canada. We hypothesize that the design of RTC addresses six challenges identified as important to quality improvement (QI) success: structural, cultural, educational, emotional, political, and physical and technical. The experience of RTC implementation is explored in semi-structured interviews with nurses (n=35) from six case study units. These units were sampled to maximize variation in exposure to RTC, location, facility size, leadership, fidelity to the RTC approach, and capacity. Our results suggest context is crucial in understanding the RTC experience. For example, a unit from a rural hospital appears strong in addressing the cultural, education and emotional challenges. Staff describe a respectful team that work well together. Early resisters “came onboard” after participating on a RTC module team, which the unit leader encouraged all staff to undertake. They also successfully aligned other quality improvement work with RTC to maximize efforts. This, and other case study results will be presented and compared with other jurisdiction’s experiences with RTC and the challenges highlighted in the literature. The findings illustrate how the design of RTC appears to assist units to organize for quality and achieve sustainable improvements. Given the national and international interest in implementing this QI approach, these results provide a timely understanding of how RTC supports change and the challenges associated with its implementation.

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## Rural Women’s Health and the Influence of Curling on Individual and Community Health: A Photovoice Study

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Beverly Leipert

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Lynn Scruby

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Heather Mair

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Women are the backbone of rural communities, yet limited resources in rural settings restrict women's ability to deal with health issues and promote their health. Engaging in recreation and team sport activities, such as curling may be one way to promote rural women's health. Curling is part of the fabric of Canadian society and central to many rural communities. However, little research has explored rural sporting activities for their implications for gender development and as ways to promote rural women's health.

A national 3 year study was conducted in three provinces and the North West Territories in Canada using feminist rural ethnography and photovoice methodologies to explore the influence of curling on the health of rural women. This presentation will describe the research findings for 16 women aged 44-75 from two rural Nova Scotia communities. The analysis of 277 photographs, transcripts of four focus groups and participant log books revealed that curling builds relationships and social connections, facilitates women's health and resiliency, and strengthens community connections and health. The curling clubs represented a hub of rural camaraderie and identity for the women and opened up new possibilities. Selected study findings, including participant photographs and quotes will be discussed to illustrate the study themes.

The findings confirm that photovoice, an innovative qualitative method, is an effective catalyst for discussion and documenting rural women's reality. Implications for practice, policy, and research will be discussed.

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### **Saving Money on the Backs of Nurses: the Objectification of Nursing Work in Hospitals**

Laurie Clune

*Ryerson University*

Ann-Marie Urban

*University of Regina*

Nursing is a high-risk profession for injury. A Canadian survey reports many nurses are in poor physical and emotional health; they sustain more musculoskeletal and violence-related injuries than other occupational groups. In this presentation, two Canadian nurse ethnographers, with a common interest in the objectification of nursing work, discuss how embedded ideologies blamed nurses for illness, and

injuries are evident in health care discourse. One author discussed how nurses, employed in a female-dominated profession, work in health care organizations that are coordinated and organized by a patriarchal ideology embedded within a military and religious history. These discourses are woven through nurses' everyday work lives, and create unhealthy work environments. Author two provides an example of how the injury management practice of early return to work fails to provide a practice setting and organizational context that will accommodate nursing work. As a result, nurses are assigned to duties, which hamper them from returning to their pre-injury positions and cause their employment with the hospital to be reconsidered. The unsuccessful return of injured nurses to employment is counter to provincial retention initiatives, which seek to sustain an adequate cadre of nurses ready and able to care for the increasing health care needs of an aging population. The authors call for a re-examination of the discourses and the underlying assumptions permeating nurses' work in order to shift the nurse's place in the hospital.

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### **Situating the Clinical Phenomenon of Breaking Bad News in Health Care System: Insights from a Grounded Theory Study in India**

Lawrence Martis

*Wilfrid Laurier University*

The need for communicative competence among health care professionals can hardly be overemphasized because research has shown that quality of interactions among patients, families, and health care professionals has implications for clinical relationships, education of care consumers, treatment adherence, and better health outcomes. Particularly, the phenomenon of 'breaking bad news' or 'truth telling' requires greater attention because it is the most challenging aspect of clinical communication and involves delivering the information about diagnosis of some life-threatening disease, poor prognosis, unresponsive treatments, and impending death. However, the existing models aimed to direct the processes of truth telling have focused on psychological responses to bad news concerning diseased bodies and emphasized the interactional skills at individual and interpersonal level. The need for examining the systemic (socio-structural) dimension of truth telling necessitated a new study.

**Method:** 27 physicians currently working in corporate, not-for-profit, and public hospitals, including some with international clinical experiences were interviewed to understand the process of breaking bad news in India. Grounded Theory Method (GTM) procedures were employed to explicate the processes underlying the meanings, attitudes, and practices of breaking bad news.

**Findings:** Analysis of data revealed that 1) Bad news is as much a socially constructed phenomenon as a biophysical reality; 2) A fragmented, sub-optimally functioning, and inequitable health system contributes to bad news and constrains truth telling, which is essential for patients' participation in decision making, and planning life transitions; 3) It might even burn out the bearers of bad news instead of bettering their communicative capacities.

Conclusion: Bad news is not the consequence of a diseased body alone but of dysfunctional health care system too. Hence the efforts related to transforming the health care system are as important as teaching interactional skills to health care providers. Invariably, this study highlights the usefulness of GTM for explaining the influence of Macro-systems on micro-level clinical interactions.

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### **Someone to Watch over You: The Parental Experience of Making Decisions Concerning PRN Administration of Antiseizure Medications to Children Living with a Life Limiting Condition**

Judy Rashotte

*Children's Hospital of Eastern Ontario*

Judy King

*University of Ottawa*

Regis Vaillancourt

*Children's Hospital of Eastern Ontario*

Betty Cragg

*University of Ottawa*

Children living with life limiting conditions are now commonly cared for by parents in the home. As a result, parents and nurses who work in respite centres face new relationship challenges. Little research has examined parental decision making associated with care giving activities, including the administration of PRN (as needed) medications. To begin to address this gap in the literature, we used an interpretive phenomenological research design to explore parental experiences of making decisions about administering PRN antiseizure medications to their child and the impact this had on their relationship with nurses. Interviews were conducted with nine parents of children who occasionally spent time at one Ontario paediatric palliative care and respite centre. The overarching theme "Under My Watch" reflected parents' experiences of being constantly engaged in bearing witness, being attentive, creating connectedness, and finding the right thing to do in each seizure situation. Doing the right thing was a balancing act associated with stopping the seizure and making the child comfortable while preventing over sedation. Four themes emerged. Being in the know involved what to know and ways of knowing. Marking time involved waiting and timekeeping. Seeking a sense of personal comfort involved developing a sense of comfort, experiencing distress and responding to distress. Making the decision involved recognizing a seizure, identifying options, weighing the options, and rethinking the decision. These findings demonstrate the complexity of parental decision making within this context and advance our understanding of the major tensions that parents face when making this type of decision.

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### **Sometimes it's The Little Things: Exploring the Relationships between Stress, Resilience And Expressions Of Subjectivity Among Immigrant Youth In Victoria BC**

Sarah Fletcher

*University of Victoria*

Immigrant youth are frequently forced to navigate multiple identities in various social and cultural contexts. Often described as living in 'multiple worlds', many youth manage this navigation very successfully, while others experience high levels of stress or tension. Starting in September of 2011, a participatory research project, carried out in partnership with the Victoria Immigrant and Refugee Centre Society (VIRCS), has been working with a group of youth researchers to explore the relationship between stress, resilience and expressions of subjectivity among immigrant youth. Through interviews, focus groups and a photovoice project, the work of the research team (made up of immigrant youth and a research facilitator) has focused on the diverse challenges that face immigrant youth, youth perspectives on stress and what could be done, from the perspective of the youth involved, to enhance resilience and support for immigrant youth in Victoria. This paper presents the preliminary findings of this participatory research project, with an emphasis placed on the photovoice findings. Focusing on the participatory nature of the photovoice approach taken in this project, the discussion will illustrate of the usefulness of this method in facilitating discussions of difficult issues, at the phenomenological level, specifically in the context of immigrant youth. Recommendations that have emerged from the project will be presented and outcomes, in terms of actions taken by the youth research team will be highlighted.

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### **Sounds of Change? Border Pedagogy Explorations of Spoken Word with LGBTQ Youth**

Susan Arai

*University of Waterloo*

This presentation recounts a moment of performance as border pedagogy; critical pedagogy and performance ethnography were merged in a spoken word workshop with gay, lesbian, bisexual, transgendered, and queer youth and their allies. Participants created, performed, and collectively explored messages of homophobia, identity, and community, confronted the juxtaposition of these messages, and unfolded possibilities for hope.

Spoken word performances were recorded and a mash-up created and played back. Mash-ups created opportunity to feel emotional weights of different tracks, hear complexity, and hold tensions as multiple tracks were played back together to represent the plurality of messages we hear in community. Mash-ups enabled us to play for change, adjusting volume on different messages and switch up which tracks were played back together. In this way, performance creates possibilities for remaking culture and self in the complexities of micropractices of power. Fieldwork was a collaborative process- it was itself was a performance where knowledge shifted from being informative to performative. As Norm Denzin describes every performance decenters agency and person through movement, disruption, action, and questioning the status quo.

At the heart of this performance and critical pedagogical endeavor was a search for understanding how participants recreate meaning (perhaps returning to reinterpret narratives of the past). In what D. Soyini Madison refers to as the spirit of our inspired oneness, participants engaged in dialogic and performative encounters. Alone we can come to understand only what we already understand; and to risk testing our perceptions of self and community in dialogue makes possible new meanings.

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### **Striving for “Controlled Co-Existence”: Living with Chronic Obstructive Pulmonary Disease:**

Adeline Cooney

*National University of Ireland, Galway*

Lorraine Mee

*National University of Ireland, Galway*

Dympna Casey

*National University of Ireland, Galway*

Kathy Murphy

*National University of Ireland, Galway*

Declan Devane

*National University of Ireland, Galway*

Bernard McCarthy

*National University of Ireland, Galway*

Chronic obstructive pulmonary disease (COPD) is a major cause of disability and death. This study aimed to understand the meaning of COPD for people and their response to this disease. This grounded theory study was part of a larger study, the PRINCE trial (Trial registration ISRCTN: ISRCTN52403063), a two-armed, single blind cluster randomised trial conducted in the primary care setting in Ireland. Participants recruited to the intervention arm received a structured education pulmonary rehabilitation programme (SEPRP). Participants (n = 26) included in the grounded theory study were recruited from the intervention arm. These participants were interviewed prior to and after the SERPS. The data reported here were drawn from the interviews conducted prior to the SEPRP. The “Theory of Co-existing with COPD” emerged and explains how people struggle to “co-exist” with COPD. Participants were found to engage in two key tasks “hiding” and “battling”. The unpredictability of COPD meant that participants found COPD hard to manage and “fit” it into their lives. The likelihood of the person with COPD maintaining and sustaining “controlled co-existence” was greater if participants knew what to do, when and how. However, some of the strategies they employed to manage COPD (e.g. pacing or limiting) were often learnt through trial and error. This paper will present the “Theory of Co-existing with COPD” and examine its implications for care.

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### **Stroke Prevention: Delivering Personalised Care**

Liz Croot

*University of Sheffield*

Fiona Campbell  
*University of Sheffield*  
Jennifer Read  
*University of Sheffield*  
Tony Ryan  
*University of Sheffield*  
G. Venables  
*University of Sheffield*

Diagnosis of transient ischaemic attack (TIA) offers a critical opportunity for stroke prevention. Our study investigated patients' experiences of TIA follow up care and explored the extent to which this facilitated behaviour change to reduce risk of future stroke. We used narrative interviews with a purposive sample of patients (n=35) from four UK National Health Service Trusts who were between two and 24 months post TIA. Participant ages ranged between 31 and 89 years. Interview topics included the TIA and events immediately afterwards, follow up care, changes to behaviour made or not made and reasons for this. Narrative and thematic analyses were carried out. We found factors such as age, co-morbidity, and knowledge about the effects of stroke contributed to patients' understanding of the personal consequences of stroke and their response to follow up advice. Patients fitted into three groups: those who did not receive information about behaviour change; those who received information but did not change behaviour and those who received information and did change behaviour. We explored variation within and between these groups. Our results indicate that follow up care is not universally available and stroke prevention advice is not always personalised to facilitate individual behaviour change. We reflect on the challenges of implementing findings from narrative research, for example, fragmenting patients' accounts of their experience into transferable 'truths'. We also describe how we are using findings to develop and evaluate services in collaboration with clinicians and commissioners to ensure all patients receive personalised follow up care.

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### **Subjective Text Interpretation in a Qualitative Study is not so "Subjective"**

Hirofumi Takagi  
*Toho University*

Although quantitative researchers frequently criticize the text interpretations in qualitative researches for their subjective results, it is not so subjective, because the language system in the brain must be structured systematically from viewpoints of linguistic structuralism and semantics. Therefore we cannot interpret the texts to be subjective.

If we are endowed with the universal grammar in our brains and our language system is generative as N. Chomsky insisted, it should be thought that our individual language systems are quite similar. K. Machida (2011) proposed that each sentence has a unique linguistic structure making for the meaning in semantics view including theme, subject, complement, predicate, time, space, fact and fiction, and so

on. Therefore the existence of linguistic structure of the sentence could control our free interpretations, and could operate to make a limited interpretation of the text by contraries.

A. Wierzbicka (1996) suggested that each language has about 60 special words called “Natural Semantic Metalanguage (NSM)”, which construct the core meaning area of each language in common without regard to the kind of language. The words included in NSM are the final words which are irreducible core of all natural languages. The existence of NSM in all languages strongly suggests that we might have common linguistic interpretation system in our brains.

These reasons described above could show “Subjective text interpretation is not so subjective”.

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### **Teaching Qualitative Research: Pedagogical Encounters with Health Care Practitioners**

Steven Jordan

*McGill University*

This paper draws on over a decade of teaching experience working with health care practitioners from a range of disciplines including physicians, nurses, occupational therapists, laboratory scientists, chemists, bio-engineers, as well as veterinarians. While providing an overview and discussion of the various strategies used to explore qualitative research with a diverse range of health care practitioners, the paper will focus on three issues: 1. The theoretical and conceptual principles used to organise and structure content for a seminar-based exploration of qualitative research in health care settings; 2. An exploration of the pedagogical encounter itself, focussing on the paradigm shift required by students from a bio-medical background in encountering a non-positivist paradigm; 3. A discussion of different approaches to assessment and evaluation in qualitative research. It is hoped that those who attend this presentation will share their own experience of teaching qualitative research, its respective problems and challenges, as well as successes and insights.

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### **Textual Mediation of Patient Work In a Stroke Prevention Clinic**

Sarah Flogen

*University of Toronto*

People who experience an episode of neurovascular impairment, such as slurred speech or sudden weakness, may be experiencing a transient ischemic attack (threatened stroke) or a minor stroke. The risk of recurrent stroke in the week after a TIA or minor stroke is 10%. The urgent goal of treatment for patients with these symptoms is stroke prevention through patient self-management of risk factors. This paper will empirically examine and describe the preliminary findings of a doctoral critical ethnography that explores the experience of socially less advantaged Torontonians who attend the clinic. Observations, interviews and textual analysis make visible the work of the patient, and how that

work is socially organized. Referral forms move patients from point to point, triage and data collection forms, brain scans and medication lists provide a glimpse inside the body; the patient work involves obtaining the scan and managing the medications. Health problems are attended to through pharmaceutical solutions. How texts direct work and enact the social organization of stroke prevention will be a focus.

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### **Thanks for Using Me: An Exploration of Exit Strategy in Qualitative Research**

Zachary Morrison

*Medicine Hat College*

Qualitative research supports the importance of establishing a relationship with participants through building comfort, trust and ultimately rapport, especially when studying sensitive topics with vulnerable populations. Acknowledging the importance placed on establishing a relationship with participants and the associated ethical considerations of negotiating access with participants for data collection, suggests equal emphasis regarding the closure of the relationship, and the ethical considerations therein. However, such consideration is lacking in the research literature. To date, understanding the dynamics involved in ending research has been on the emotional strain experienced by researchers, the role of stakeholders (i.e. institutions and funding organizations) in determining closure, and the obligation some researchers feel to define new relationships with participants. This expository and reflective research illustrates the complexity of 'ending' a study and purposes a theoretical shift from researcher-participant to participant-researcher relationship. Through a synthesis of the literature, and the powerful words voiced in a qualitative case study involving overweight adolescent boys reveal the potential emotional investment participants make regarding their research involvement. The well-being, protection and safety of participants are not simply subject to access and data collection, but necessarily include negotiated safe closure. Given what is potentially at stake for participants in qualitative research, there is a moral and ethical imperative to enter into the dialogue of closure. Researchers, research supervisors, and human subject ethics committees are urged to establish protocols to guide how research relationships are ended within the context of qualitative methods, particularly with respect to vulnerable populations.

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### **The Adoption of a Community Participation Framework in Community Health Centres in Ontario: Using an Integrated Knowledge Translation Approach**

Stephanie Montesanti

*McMaster University*

John N. Lavis

*McMaster University*

Julia Abelson

*McMaster University*

This study builds on a previous case study research of community participation initiatives of four Community Health Centres (CHCs) in Ontario. One focus group was facilitated at each CHC to allow CHC staff working with the community to be actively involved in the development of a framework to guide community participation initiatives within participating CHCs. We also examined the factors that enable the adoption of a community participation framework to guide community participation initiatives within each CHC. A proposed conceptual framework on the design of community participation strategies with marginalized communities was presented to CHC staff. Participants then worked together to examine the framework for its applicability to the CHC context. Specific questions on the conceptual framework were asked to the focus groups. Participants were given allocated time to revise the proposed framework in order for it to be most useful in their own CHC. The primary aim of the focus group is to address the “context-specificity” of the framework and to make it relevant to its end users. Focus group participants described the challenges of developing a framework for community participation with marginalized populations that would account for inevitable changes within the community structure and the political environment that might occur throughout the process of participation. They described that community participation cannot be depicted as a “cookie-cutter” approach with a logical process that be applied to any community health issue. Rather, from their experience participation with marginalized communities is “messy” and a guiding framework should identify the structural and community-level changes that may arise when engaging marginalized communities.

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### **The Conduct of Culturally Appropriate Qualitative Oral Health Research in Aboriginal Community Controlled Health Services**

David Walker

*University of Sydney*

Ngiare Brown

*University of Sydney*

Anthony Blinkhorn

*University of Sydney*

Oral disease has a major impact on children and infants in Aboriginal communities. Although many communities face this impact with limited access to dental personnel, most communities have access to care by Aboriginal Health Workers who are key community health personnel. The development of an oral health role for Aboriginal Health Workers is therefore a potentially important strategy in improved Aboriginal community oral health.

This study identifies steps taken to support the conduct of culturally appropriate qualitative health research focussing on Aboriginal Health Worker oral health role development in Aboriginal Community Controlled Health Services in New South Wales, Australia.

The development of the research was guided by national Australian guidelines for the conduct of research in Aboriginal communities. The research process included ongoing consultation with participating Aboriginal Community Controlled Health Services and the establishment of an Indigenous Reference Group which provided practical cultural guidance throughout the project.

Training in the prevention of early childhood caries was provided to Aboriginal Health Workers in six Aboriginal Community Controlled Health Services. Semi-structured interviews were conducted with 16 Aboriginal Health Workers and 6 senior managers of these health services to evaluate the development of the training and explore next steps in sustainable role development.

This qualitative health research led to significant changes in training design and delivery supporting sustainable role development in an often neglected but important area of Aboriginal community health.

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### **The Experience of Donating or Receiving a Kidney through Living Kidney Donation: An Interpretative Phenomenological Analysis of Ten Cases**

Deborah Ummel

*Université de Montréal*

Marie Achille

*Université de Montréal*

Given the shortage of organs from deceased persons, living kidney donation (LKD) is currently being promoted and practised in all western countries despite the fact that some studies have found it to be related to major psychological challenges. The goal of the current study is to describe the experience of donating or receiving a kidney through LKD.

Five donors and five recipients were interviewed individually. Participants included in the study were diversified in terms of the type of the relationship between the donor and the recipient, and the time elapsed since donation. Data was analyzed following the principles of Interpretative Phenomenological Analysis.

Results obtained from the transversal analysis of the five donor cases and the five recipient cases will be presented in order to describe the overall experience of LKD through the perspective of either donors or recipients. This presentation will emphasize the common experiences of donors and recipients, and also some particularities of individual donor and recipient cases.

Having a more complete picture of the experience of donating or receiving a kidney through LDK will provide in-depth information that can be shared with future donor and recipient candidates about the possible effects of LKD. In addition, our results may serve to promote individuals' psychological health and well-being in the context of chronic kidney disease.

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## **The Experience of the Intimate Dyad after Weight Loss Surgery: A Qualitative Description**

Kristen G. Barbee

*Wingate University*

Obesity is a condition that has reached epidemic proportions in the United States. Weight Loss Surgery (WLS) has been established as a safe and effective means of long-term weight control. There is a gap in the literature related to the experience of the dyad after WLS. The purpose of this study was to elicit the experience of the intimate dyad after one member underwent WLS.

A qualitative descriptive design was used. Ten intimate dyads were interviewed using a semi-structured interview guide, with each individual interviewed separately in order to gain a richer description. The interviews were analyzed individually using Colaizzi's (1978) method of data analysis with a secondary dyadic analysis using the method outlined by Eisikovits and Koren (2010).

Four themes were developed out of the descriptions: 1) no longer a slave to food; 2) it's both good and bad; 3) surgery is just a tool, not the solution; and 4) support and accommodation. No new themes were developed after the dyadic analysis. The dyadic analysis revealed a great deal of overlap between the dyadic member's stories and the use of positive dyadic coping.

WLS affects both the individual and the intimate partner. Healthcare needs to understand how the intimate dyad experiences WLS in order to develop better preoperative and postoperative education programs to maximize positive outcomes. Dyadic analysis can provide a unique perspective in studies related to health concerns.

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## **The Experiences of Family Caregivers Caring for a Relative with Early- Onset Dementia: A Qualitative Study**

Rachel Flynn

*University of Alberta*

Helen Mulcahy

*University College of Cork*

It is estimated there are 3,500 people in Ireland under the age of 65 with Early Onset Dementia (EOD). In Ireland the support structures for persons with EOD are within the family. Care giving is associated with a high risk of burden, putting a large amount of physical, psychological, emotional and social strain on both the patient and the family. Currently, there is limited literature examining caregiver burden in EOD carers; therefore, the aim of my Master's thesis was to explore experiences of family caregivers who are caring for a relative with EOD in Ireland; to identify the impact caregiving can have on the caregiver socially, financially, emotionally and physically; to explore the factors that help these caregivers cope; and, to establish the needs of these caregivers in relation to supports and services. I conducted face to

face, semi-structured, in-depth interviews with 7 caregivers. Using thematic analysis four themes emerged from the data: 1) diagnostic problems; 2) impact on the carer and their family; and, 3) relationship change and 4) lack of knowledge and support. It is critical to share the stories of my participants and their families in order to highlight the challenges of EOD in relation to existing supports and services in Ireland. I would also like to compare and contrast these findings with the supports and services available to EOD caregivers in Canada in order to offer some solutions for positive change.

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### **The Factors Impeding the Public Health System Reform in Erbil Province, Iraq**

Ashraf Al-Hamadani

*The International Committee of the Red Cross*

Mark Edwards

*The University of Liverpool / Laureat Online Education*

The poor health outcomes in Erbil province have been attributed to the inability to address the shortfalls in the public health system through evidence based reform. Calls for health system reform started in 2004, however, no significant changes have been achieved to date. This research examines the factors impeding the reform.

In-depth, semi-structured interviews were conducted with eleven purposely selected health policy makers. The interviews involved discussions around the major challenges in the public health system, like: human resource management, primary health care and the private/public articulation, and why these issues are not being adequately addressed.

Five categories of impeding factors were highlighted. The historical category includes the political/economic instability, mistrusting the government, the corruption and the dysfunctional employment system. The ethical factors include the focus on the income-generating medical specialties, with the domination of the private practice at the expense of public facilities. Cultural factors are the tribal background, nepotism and resistance to change. The politicized allocation of the policy making posts and the weak political support to the health sector are the major political factors. Institutional factors include the old and centralized management system, which lacks clear strategies and skilled managerial expertise.

The intricate network of inter-related/dependent impeding factors has shown that the health system reform in Erbil is not a straightforward task. Without addressing these background factors; the discussions about reform options will remain on paper. A comprehensive, cohesive, and evidence based reform that considers all the mentioned factors would have better chances of success.

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### **The Life-stories of Iranian University Students Who Attempted Suicide: A Structural Analysis**

Maryam Gholamrezaei

*McGill University*

Leili Panaghi

*Shahid Beheshti University*

Liane C. Pereira

*McGill University*

Amir Ali Nojournian

*Shahid Beheshti University*

Suicide rates among young people have grown recently and calls for research to understand the nature of suicide in context. Narrative analysis is a language-based method that considers humans as natural story tellers and deems life-narratives as useful in studying the self and identity because they are culturally accepted stories (Bruner, 1990). The purpose of this study was to use a structural perspective to analyze the life-narratives of Iranian university students who had attempted suicide to better understand suicide in context. Nine Iranian university students (5 women; mean age = 22, SD = 2.53) who had sought professional help in their student counselling center were interviewed using McAdams' Life Story Interview; these interviews were then transcribed and analyzed using methods adopted from Greimas' narratology to find common structures in plots, actants or "characters", binary oppositions, and semiotic squares. Results indicated a pattern in the story plots of the participants whose stories began with a major conflict with little explanatory detail and ended with little resolution, and also in the nature of actants, with fathers being the most prominent actant in participants' life stories. Furthermore, based on analyzing plots, actants, and binary oppositions, these major semiotic squares appeared: gender role, humiliation, failure, identity, rejection and justice. These units of meaning were repeated in all nine stories, as were many structural patterns, and these commonalities may have implications for the identity confusion and development in individuals who have attempted suicide. These implications and considerations for future research will be discussed.

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### **The Organ Transplant List as Genre: Insights from an Ethnographic Study**

Allan McDougall

*Western University*

Lorelei Lingard

*Western University*

Catherine Schryer

*Ryerson University*

Marlee Spafford

*University of Waterloo*

Mark Levstik

*Western University*

Natasha Chandok

*Western University*

Patients requiring transplantation face the fact that one or more of their organs will irrecoverably fail. These patients may be critically ill or near-fully functioning. In each case, new organs are required to extend and improve patients' lives. Some patients wait years for their new organ. Some die waiting. Collectively, this group of patients is registered and situated on the organ transplant list, the central genre of transplant care.

As a complement past work on health care genres, our presentation is the first to analyze the transplant list from the perspective of rhetorical genre studies. With data gathered from a longitudinal, ethnographic study of a tertiary care transplant team, this presentation will explore the organ transplant list as genre. Our research asks, how is the list genre used in patient care? How is it invoked in healthcare team discourse? What is the list's social action on the distributed healthcare team?

Our findings observe that, as both a document and a group of people, 'the list' is the result of a complex process of decisions and negotiations at an institutional and governmental level. This presentation will discuss the social action of the list, such as when teams are routinely required to list, to de-list, to activate or to hold patients' statuses on the organ transplant list. Negotiations around a patient's status on the list will also be discussed, specifically focusing on the negotiated contract between providers and patients about what it means to be 'listable'.

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### **The Participation of Marginalized Communities in Local Health System Planning: The Development of a Conceptual Framework using Critical Interpretative Synthesis**

Stephanie Montesanti

*McMaster University*

Julia Abelson

*McMaster University*

John N. Lavis

*McMaster University*

Jim R. Dunn

*McMaster University*

Qualitative research has traditionally been excluded from systematic reviews. Critiques of conventional systematic review methodology have focused on both the nature of the truth claims it can make and its inappropriateness for some forms of review questions. An alternative review methodology is a Critical Interpretative Synthesis (CIS) to synthesize diverse forms of evidence. CIS is rooted firmly in qualitative tradition of inquiry and draws on interpretive synthesis methods such as meta-ethnography. This review methodology allows for the conceptual translation of quantitative and qualitative studies, as well as

non-empirical papers, and is explicitly oriented towards theory building. The objective of this synthesis is two-fold: 1) to understand the barriers and facilitators to participation with marginalized communities in local health system planning; and 2) to determine the appropriate design features and components of a participation approach involving marginalized communities. The findings of the synthesis review suggest that the planning for participation with marginalized communities should include an assessment of community needs, an understanding of the community's history, adapting the participation strategy to the local context, and fostering relationships and trust with the community. An effective participation approach used should emphasize greater community control over planning and decision-making, diverse representation across sub-groups in the community, and fostering community empowerment through capacity building. Principles of community participation demonstrate the benefits of participation both individual (e.g., self-determination) and collective (improved social networks and increased community capacity). However, there are limited evaluations of participation approaches with marginalized communities to determine 'how' certain outcomes of participation are achieved. Lastly, barriers were described to include the challenges with addressing complex health needs in the community, limited knowledge and capacity within the community, language and cultural diversity, and funding and time constraints of sponsoring organizations. A conceptual framework was developed to illustrate the barriers to participation, and the components and features of a participation approach to facilitate participation with marginalized communities.

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### **The Phenomenon of Embodiment and the Birthing Experience**

Susan E. Fleming

*Washington State University*

Roxanne Vandermause

*Washington State University*

The phenomenon of embodiment has been explored in philosophical literature and can be applied to health care experiences. It is exemplified no better than in the birthing process. In U.S. hospitals technology (e.g. monitors, epidurals) often becomes central in the birthing process and mothers must interact with this technology as well as with other persons during their deliveries. Such experiences require a new way for women to embody the birthing process. This new form of embodiment manifested in a recent Heideggerian phenomenological study of the experiences of grand multiparae (5 or more births) birthing in US hospitals. There is a national concerted effort to eliminate elective inductions prior to 39 weeks, which can result in better maternal and neonatal outcomes. These changes can promote more "natural births" where women are embodied in the experience. While such changes are valuable, there is also a process whereby women may adjust their embodied experience to include technological interventions. This highlights the need for further exploration and interpretation of this phenomenon. To this end, an extended analysis of the theme, "Embodiment of Pregnancy, Birthing and Feeding" from the original study will be undertaken in this presentation, along with a discussion of how women view their bodies during birthing, expulsion and feeding, how they can work

with their bodies and their babies during birth, and how an understanding of this process on the part of providers can enhance health care practice.

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### **The Professional Codevelopment Group: An Innovative Framework in the World of Participatory Action Research**

Sophie Langlois

*Université de Montréal*

Lyne Lalonde

*Université de Montréal*

Johanne Goudreau

*Université de Montréal*

Bridging the gap between theory and practice is crucial if we want to prepare health care professionals to meet tomorrow's challenges. One of the solutions to join these two worlds is participatory action research (PAR). Unfortunately, like other research designs, PAR shows some limitations according to the lack of clear methodological frameworks because of its relatively recent utilization (Munten, van den Bogaard, Cox, Garretsen, & Bongers, 2010). Therefore, this presentation aims to address this problematic and to propose a framework inspired by the professional codevelopment group (Payette, & Champagne, 1997; Hoffner-Lesure, & Delaunay, 2011) to guide data collection and analysis in PAR. The professional codevelopment group constitutes a structured educational approach based on the principles of experiential learning in small groups elaborated by Lewin (1946, 1947), action learning and adult education as described by Revans (1978, 1982, 1987), and individual/collective reflective practice as defined by Schön (1983, 1994) and Argyris (1995).

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### **The Professional Socialisation of Paramedics: the Transition from University Student to Practising Paramedic**

Scott Devenish

*Queensland University of Technology*

Michele Clark

*Queensland University of Technology*

MaryLou Fleming

*Queensland University of Technology*

Stephen Loftus

*Charles Sturt University*

Socialisation is defined as the process by which professionals learn the values, behaviours and attitudes necessary to assume their chosen professional role. The professional socialisation process consists of three phases namely, pre socialisation (anticipatory), formal socialisation (university) and post formal

(workplace) socialisation phases. This presentation explores the experiences of paramedics during their transition from the formal socialisation phase as a student to the post-formal phase on gaining employment with an ambulance service.

Participants were sought from several of Australia's larger ambulance services and UK NHS Ambulance Trusts to take part in this study. Participants were required to be university educated and employed in a professional consolidation year. Data collection was via face to face semi structured interviews. A thematic analysis of the interview transcripts using grounded theory was undertaken.

The results show that the excitement of gaining employment with an ambulance service was equaled by fear. Once employed, paramedics encountered the reality shock of full time work. They were confronted with the ambulance workplace culture, and felt the need to conform to this culture to be accepted by work colleagues. Paramedic interns learned to cope with a range of challenging situations, and to deal with the reality of paramedic practice, where not every case is an urgent life saving endeavour.

In conclusion, the transition from university student to paramedic intern can be a very difficult experience. Interns felt the need to assimilate into the culture to be accepted, and there was a perceived dissonance between the university and ambulance cultures.

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### **The Reciprocating Confidence Process in Rural Preceptorship**

Deirdre Jackman

*University of Alberta*

Florence Myrick

*University of Alberta*

Rural preceptorship denotes the tenets of traditional preceptorship in cohesion with the contextual reality of rural nursing practice. Preceptorship entails the one to one pairing of a nursing student with a practicing registered nurse to foster socialization, competence and confidence. The prefix 'rural' denotes a practice setting according to the literature is dynamic and complex. Rural nursing, therefore, requires significant knowledge and practice autonomy. From an educational perspective the ability of the student to gain confidence in her/his knowledge and practice can be daunting. The purpose of this presentation is to provide findings from a larger grounded theory study in which preceptorship was explored with key participants within a rural preceptorship experience. Reciprocating confidence was found to be an essential theme in order to promote student learning. This reciprocation was based on a relational trust between the preceptor and the student in which the student did not build self-confidence in isolation but relied on the preceptor's teaching/learning engagement to promote the student's confidence. Cyclical confidence contributed to the advancement of student knowledge and practice. Study findings suggest that because of the complexity of rural nursing practice the components of reciprocating confidence are relevant to promoting an authentic transition for the nursing student to the role of 'rural

nurse'. In addition, high levels of confidence can contribute to recruitment and retention of graduates to the rural setting.

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### **The Resident Wellness PAR Project: Notions of “Wellness” by Residents Living in LTC (Long-Term Care) Homes**

Kimberly Lopez

*University of Waterloo*

Sherry Dupuis

*University of Waterloo*

Persons 65 years or older are the fastest growing demographic in Canada (Government of Canada, 2002) and the need for 24-hour care and LTC support will continue to rise. An association is typically drawn between death and dying and the movement into LTC homes. Recent culture change initiatives are exploring ways to transform LTC homes into places of "living". Leisure is essential for promoting "living" and supporting wellness in residents. The notion of "living" in LTC shifts emphasis away from illness and death to placing value on wellness.

This participatory action research (PAR) study aimed to understand wellness from residents' perspectives and the role leisure plays in their wellness. PAR partners (family/care partners, staff, and residents) collaboratively planned how to best attain, interpret, and disseminate resident perspectives on wellness and required supports. Guiding questions included: (1) What does wellness mean to residents living in LTC? (2) What does a 'well' LTC home look like to residents? (3) What is the nature of the relationship between leisure and wellness from a resident perspective? (4) How can those involved in LTC support resident wellness?

Wellness for residents living in LTC homes encompassed four interconnected and fluid domains of life: my home, my relationships, my self and my activities. Leisure served as a space to nurture wellness in all of these areas. The new resident wellness model fills an important gap in the literature and provides key insights on how to create well LTC homes for all residents.

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### **The Sharing of Phenomenological Narrative: Fulfilling the Wishes of Couples Surviving Prostate Cancer**

Alicia Rivero-Vergne

*Inter American University, Metropolitan Campus*

Reinaldo Berrios Rivera

*University of Puerto Rico Rio Piedras Campus*

In Puerto Rico prostate cancer is the cancer most diagnosed in men, with gradually increasing survival rates. Treatment side effects as urinary incontinence, erectile dysfunction, loss of libido, among others,

not only affect the patient but also his spouse. However, there has been no evidence based research regarding the psychosocial aspect of couples' adaptation to treatment related health outcomes and survivorship.

A phenomenological approach was used to understand the experience of ten couples surviving prostate cancer. In depth interviews were conducted simultaneously, the male researcher interviewed the men and the female researcher their spouses. Content analysis yielded relevant implications for practice.

Themes identified were: resistance to be tested for prostate cancer, reaction to diagnosis, the emotional impact of dealing with secondary effects and co-constructing the marital relationship. In a Latino cultural context where "machismo" abounds and discussing intimate matters that affect couples is not common, the interviews provided participants the first opportunity to fully discuss their experiences. They urged researchers to share findings with physicians, health providers and other prostate cancer patients; as such information would have helped them cope better during and after treatment.

In order to stimulate a discussion and provide insights into these couple's needs so that psychosocial issues are attended to, we distributed to fifty physicians (oncologists, urologists) our research findings in a book format. With the purpose of enriching medical curricula we are presenting our results to medical and health related graduate schools. We believe these discussions will influence health care practice in Puerto Rico.

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### **The Teaching Support Initiative (TSI): Fostering Quality Teaching and Learning through Ongoing Professional Development**

Florence Myrick

*University of Alberta*

Pauline Paul

*University of Alberta*

Deirdre Jackman

*University of Alberta*

Derek Sellman

*University of Alberta*

Azizah Scully

*University of Alberta*

Katherine Melo

*University of Alberta*

Wendy Caplan

*University of Alberta*

Student learning is contingent on quality teaching which is invariably reliant on teacher support. To facilitate individual faculty into their academic role and support them in their teaching, it is important to cultivate an environment of professional enrichment, collegiality, respect, and one which translates into quality teaching and learning for the student. To foster such an environment the Faculty of Nursing has created the Teaching Support Initiative (TSI), a face-to-face/ web-based program designed to provide ongoing professional development. The purpose of this particular project is to develop and evaluate a self-paced online program as a TSI feature to support faculty's ongoing teaching/earning needs. This program will comprise a series of learning modules, quandary decision-making mazes, e-portfolios, case studies and voice over power point sessions. The purpose of this particular study is to determine how this self-paced online program: a) influences the teaching practices of faculty; and b) supports and contributes to faculty approach to teaching and learning. Semi-structured interviews will be conducted with a sample of 30 faculty participants and analyzed using thematic analysis. Data collection will comprise tape-recorded interviews. Demographic data will be obtained from all participants prior to these interviews. Using the findings of this study to evaluate and refine this program, the researchers will then conduct a grounded theory study to examine how this approach to teacher preparation is reflected in student outcomes. This project has the capacity to significantly enhance quality teaching and learning by supporting individual faculty to effectively and competently assume their teacher role.

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### **The Use of Participatory Research to Promote Dialogue in a Mental Health Institution**

Ronna Schwartz

*McGill University Health Centre*

A recovery paradigm, based on hope, agency, responsibility and empowerment of individuals with severe mental health problems, is a guiding principle for the transformation of mental health services both internationally and nationally. The presentation will describe the findings of a participatory project which was innovative in its intent to bring mental health service users and providers into face-to face dialogue, within an institutional setting. The sample consisted of three occupational therapists, a psychiatrist, an academic-clinician, and five service users. The objectives were to: (1) understand the values of recovery within a local context; and (2) pilot if and how such a process could provide a sustainable forum for ongoing dialogue in an institutional setting. Participatory Action Research (PAR) involves participants in the development of the research question, as well as design, interpretation, dissemination and/or implementation. Methods were informed by narrative-phenomenological ethnography and organizational theory. Participants generated data over twelve weeks through telling stories (to reveal values) and dialogue (to increase reflexivity). Transcriptions of audio-taped group sessions were de-identified and made accessible to all participants, who contributed to both the thematic and narrative analysis. Significant interpersonal and intrapersonal tensions were named, and conditions for a more sustainable process of knowledge exchange were explored. The project revealed both the challenges with situating research within an institutional setting (power, vulnerability, and hierarchy of knowledge) as well as positive changes in professional attitudes and increased reflexivity.

The project underscored the need and the potential for professional-service user partnerships in mental health care.

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### **Theory, Instrument, and Intervention Development in an Ethnographic Study of Long-Term Care Decision-Making in Rural African Americans**

Yvonne Eaves

*Kennesaw State University*

Health disparities among racial and ethnic minority older adults result in reduced quality of life, an inability to remain active and productive, higher healthcare costs, and illness related transitions, including institutionalization. Yet, there is limited research that explicates how to measure such disparity related transitions in rural older African Americans or that reports tailored long-term care interventions for this group. Therefore, the purposes of this longitudinal, ethnographic study were to: (a) identify and analyze episodic and/or emergent health events that resulted in caregiving transitions, namely long-term care (LTC) decision-making, in rural African American families; and (b) develop a long-term care planning (LTCP) intervention to assist rural African American families in planning for and responding to caregiving transitions and LTC decision-making. During the study the ethnographic data was also used to develop a decision-making instrument for rural African American caregivers. Meleis' Transitions Theory was used to guide the study and to further understanding of the interrelationships among different types of transitions that commonly occur in older adulthood. The sample included eleven caregiving families comprised of 11 care recipients (70-86 years) and 11 caregivers (27-63 years). Semi-structured audio-taped interviews, fieldnotes, and focused observations were used to generate data. Ethnographic analytic techniques were used to code and classify the data and then formulate meaningful categories, themes, and patterns into an explanatory framework. A culturally relevant tailored LTCP intervention was developed based on this ethnographic data. The LTCP intervention provides families with specific strategies for decision-making and LTC planning in response to caregiving transitions.

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### **Translation of Qualitative Findings for Practical Use: Poetic Transcription**

Sharyl Toscano

*University of Alaska*

The aim of this presentation is to discuss the method of poetic transcription as a means to translate qualitative research findings for use in the practice setting. The presenter will use a case study approach to describe how the resulting theory from a grounded theory research design (Theory of Female adolescents' safety as determined by the dynamics of the Circle, 2007) was translated through secondary analysis using poetic transcription. Anecdotal stories of how Trisha's story (It Wasn't Always That Way, 2007) has been used in education, screening, and prevention since 2007 will be discussed.

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## **Understanding Age-Related Influences on Cancer Treatment Decision Making: A Review of Grounded Theory Studies**

Fay J. Strohschein

*McGill University*

Joan L. Bottorff

*University of British Columbia Okanagan*

Rita S. Schreiber

*University of Victoria*

Carmen G. Loiselle

*McGill University*

Cancer occurs disproportionately among older adults, for whom variations in health/functional status, decreases in social support networks, lack of clear clinical guidelines, and increased tension between quality versus quantity of life present challenges to treatment-related decision making. Understanding age-related influences on decisional processes is needed to offer optimal support. Grounded theory is a well-established qualitative methodology designed to understand processes. I examine grounded theory studies of cancer treatment decision making (CTDM) that include the patient perspective, assessing methods used and contributions to understanding of CTDM in general, and of age-related influences in particular.

Twenty-three relevant studies, published between 1985 and 2012, were identified. Authors who described using core methods of grounded theory contributed greater theoretical insight (e.g. typology of decision making behavior, identification of influencing factors, and conceptualization of phases) than studies where core methods were absent or poorly defined. Findings challenge assumptions of existing models (e.g. rationality, perception of choice, autonomy, linearity, and CTDM as a single event), highlighting instead the ongoing nature of CTDM and important relational/contextual influences, such as social roles/responsibilities, cancer experiences of family members/friends, and health/social care systems. Although the influence of age is often noted, only 6 studies specifically considered older adults or included analysis by age. These findings suggest that age-related differences in desire for participation, family involvement, and information/options provided are important considerations in theorizing about CTDM. New directions for future grounded theory studies include prospective exploration of CTDM, data collection methods beyond single interviews, and theoretical sensitivity to age-related influences.

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## **Understanding *Confianza* in the Context of Health for Mexicans in an Urban Community and implications for Care: A Focused Ethnography**

Rick Zoucha

*Duquesne University*

The purpose of this study was to explore the perception and meaning of confianza in the context of health for Mexicans in an urban community. The number of Mexican immigrants is increasing every year in the United States and abroad. Little is known about confianza in the context of health for Mexicans. The sheer numbers of Mexicans in the United States suggest that seeking to understand confianza in the context of the Mexican culture is appropriate, beneficial and significant to the health of this population regarding nursing and healthcare. A qualitative focused ethnography method was used for this study. The research process included cultural immersion, observation-participation approach, writing field notes and semi-structured interviews with informants. Leininger's Four Phases of qualitative data analysis was used for this study. A voluntary convenience sample (ages 18-90; n=27, 20 female, 7 male) was sought until saturation of the data occurred. Themes identified in the final phase of analysis were: 1. Confianza is essential and needed in the relationship with health care professionals for potential healthy outcomes 2. Confianza is mutual and circular and strengthens and becomes anticipatory over time 3. If confidence in the health care provider and or institution is lost then the people will not return for care. 4. Confianza is reciprocal, mutual, mutuality increases over time, deepening, trust over time. Individuals who may emigrate from Mexico to other countries may bring with them the beliefs and values of confianza to their experience with the health care providers globally.

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#### **Understanding Health and Treatment Decision-Making among Youth with Severe Hemophilia: a Qualitative Approach**

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The study objective was to explore attitudes about health and treatment decision-making from the perspectives of young men (15-29 years) with severe hemophilia A or B in Canada. Specific goals were: to identify the factors that affect young people's treatment and management decisions, explore inter-relationships between factors, and develop an understanding of treatment decision-making to assist healthcare providers with communication strategies to ensure optimal, individualized client care. Data were collected using semi-structured interviews, managed using NVivo 9 software and analyzed using the Framework method (NatCen, UK). Fifteen interviews were conducted with participants from three sites across Canada. The major factors involved in treatment decision-making were: disease knowledge and information (acquired from: the hemophilia treatment centre, parents, involvement in hemophilia community, and lived experience including: bleeding history and presence or absence of trouble or target joints and/or inhibitors); childhood disease experiences and type of treatment; activity level; and physical and situational cues to treat. The Framework method facilitated analysis of the inter-relationships between factors and resulted in a typology of four different 'types'/approaches to treatment: routine prophylaxis – rigid, routine prophylaxis – lifestyle cues, situational prophylaxis, and no prophylaxis. Treatment decision-making among young men with hemophilia is complex, affected by numerous factors. Analysis of the inter-relationships between factors revealed important differences in how individuals with hemophilia approach and make decisions about treatment using factor concentrate. Until now, this variation has not been systematically explored and documented. This typology can be used to enhance client-provider communication and individualize treatment planning, care, and educational interventions.

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### **Understanding Pediatric Healthcare Needs While in Shelter: Mothers Perspectives**

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Karen Hudson

*Children's Hospital of Philadelphia*

Rosemary Frasso

*University of Pennsylvania*

Joyce Chang

*University of Pennsylvania*

Nishika Vidanage

*University of Pennsylvania*

Children experiencing homelessness have more medical illnesses and poorer oral health than their housed counterparts, yet little is known about the impact shelters have on pediatric healthcare utilization. A qualitative study was conducted to explore maternal perceptions of the healthcare needs of children in shelter. Additionally, we explored how residing in a shelter influences utilization of primary and emergency pediatric care. In-depth interviews of mothers of children experiencing homelessness were conducted, audio taped, transcribed verbatim and analyzed using qualitative coding methods and Nvivo9 Software. The analysis was guided by the Andersen Model of healthcare use by vulnerable

populations. Results showed that mothers in shelter identified predisposing, enabling, and need factors that influenced their preventive and emergent pediatric care use for their children. Additionally, several themes emerged that shed light on the unique challenges faced by mothers in shelter who are navigating the healthcare system. Mothers reported that access to preventive and emergent care was facilitated by shelter staff and volunteers. They also reported that common barriers to pediatric care (including lack of transportation, or funds for co-pays) were not unique to women living in shelter. Continuity of care was not disrupted by shelters stays and making a pediatric appointment was not complicated by living in a shelter, however, remembering the appointment and getting to the appointment was often challenging. Transportation and communication barriers faced by mothers before they lived in the shelter persisted after moving to a shelter. However, shelter staff members often help women overcome these barriers.

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### **Understanding Reflection from the Perspective of Baccalaureate Nursing Students**

Deborah Greenawald

*Alvernia University*

Nurse educators are seeking to meet the needs of students with diverse learning characteristics within increasingly complex academic and clinical environments. One strategy that has been used is reflection. There is, however, a lack of consensus among scholars about the specific nature of reflection. The purpose of this study was to describe reflection from the perspective of baccalaureate nursing students. Using a qualitative descriptive design within a naturalistic paradigm, participants were individually interviewed to answer the question: "What is the nature of reflection for undergraduate nursing students?" This design facilitated careful examination of individual responses and allowed for the examination of common properties in the data to discern emerging themes through constant content comparison. Five main themes were identified in the analysis of interview transcripts, including: Looking back to deepen understanding, Being mindful of thoughts and feelings, Gaining perspective, Giving words to experiences and emotions that have no right or wrong answer, and Using reflection for learning. Student quotes gave evidence that reflection is a valued practice among undergraduate nursing students and contributed positively to their education. The findings from this study provided information heretofore not addressed in the literature about the perceptions of undergraduate nursing students regarding reflection. Such information will allow nurse educators to better understand and contextualize its use for teaching and learning. Most students interviewed stated explicitly that they valued reflection and anticipated using it in their future professional practice, reinforcing the importance of including reflective activities in both undergraduate nursing education and lifelong learning.

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## Understanding the Meaning of Mental Health and Illness in an Urban Nicaraguan Barrio: A Focused Ethnography

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Leah Vota Cunningham

*Duquesne University*

Olma Zelaya

*Polytechnic University of Nicaragua (UPOLI)*

The purpose of this study was to discover the meaning of mental health and illness of residents of an urban Nicaraguan community. The research questions that guided the study were: What are the cultural perceptions and meaning of mental health of residents of an urban Nicaraguan community? What are the cultural perceptions and meaning of mental illness of residents of an urban Nicaraguan community? What is the culturally congruent process of promoting mental health and treating mental illness in this community? A qualitative focused ethnography method was used for this study and included: observation-participation, writing and interpreting field notes, semi-structured individual interviews and focus groups. Leininger's Four Phases of qualitative data analysis was used for this study. Thirty-six individual interviews were conducted, two focus groups one with nurses working in the community and one with eight families living in the barrio. The research site was a barrio in Managua, Nicaragua. The final phase of data analysis resulted in the following themes: A person is mentally healthy as long as they control and/or do not experience the "loss of five 5 senses". Mental illness is a result of living a hard life rooted in cultural etiology (environment, economic, educational, religion, legal/political) and culminating in a crisis and loss of the 5 senses. Depression, anxiety, drug abuse, violence and stress are part of life and not considered mental illness. Nurses and *brigadistas* can prevent and treat mental illness through their personal involvement with individuals and families in the community.

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## Using Photo-Voice as a Method in Qualitative Health Research

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Maria Stuttaford

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Leslie London

*University of Cape Town*

Photo-voice is a method used in qualitative public health research to uncover health issues of greatest concern to communities and to study the lives of individuals within their context. In addition, photo-voice is often used for community health needs analysis. This kind of community-driven public health

research could inform both theory and policy making. In addition, interventions could be improved through contact with the real needs of communities.

Achieving the right to health requires that those most at risk of violations of their rights understand their rights entitlements so as to take actions for change. The aim of this study was to use photovoice to explore how members of a community-based organisation view health and human rights.

Participants were given disposable cameras to take photos of health and human rights issues. The developed photos were then used to elicit responses in interviews and data was thematically analysed jointly by both the researcher and the photographers.

Results demonstrate the potential role photo-voice could play in facilitating the collection of rich contextual data and looks at some of the outcomes this method had for participant photographers in changing the conditions which increase their vulnerability.

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### Using the Internet to Gather Credible Qualitative Data from Vulnerable Populations

Jeffery Adams

*Massey University*

Stephen Neville

*Massey University*

Catherine Cook

*Massey University*

Collecting high quality data from groups identified as vulnerable is a challenging process requiring skill and sensitivity on the part of researchers. In particular the use of qualitative data has been found to be highly relevant when undertaking studies with these populations, especially for research which critiques dominant groups that cause oppression or those that foreground the voices of vulnerable people. While traditional data collection methods are well established for this purpose, the Internet offers many additional methods. However despite the Internet being very familiar to most people, some researchers remain hesitant to incorporate Internet-based data collection strategies into research projects. This presentation illustrates the Internet as a useful medium for collecting qualitative data. It outlines and critiques three Internet-based methods for collecting solicited qualitative data (online qualitative survey/questionnaire, email interview, and synchronous online interview). Examples are provided from research undertaken by us with groups often identified as vulnerable: men who have sex with men (MSM), women who have been diagnosed with a sexually transmitted infection, and sexual minority populations with/without mental health issues. Our experience in employing online technologies has been successful in encouraging participation of groups who are hard to reach and/or vulnerable. While literature is available outlining specific research methods useful for collecting data from vulnerable populations, little is available that reports on the practical application of these Internet-based data

collection methods for people from these populations. This presentation will encourage researchers to consider and embrace these technologies when appropriate.

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### **Waiting for Contact: a Phenomenological Exploration of Waiting for WLS**

Nicole Glenn

*University of Alberta*

Weight loss surgery (WLS) is a growing treatment for morbid obesity. Increasing demand, however, has meant long queues with the average surgical wait times in Canada measuring approximately 5 years. There is a dearth of literature on WLS--- related outcomes. However, there is little qualitative scholarship and none that has questioned the pre---surgical experience from a phenomenological perspective. Thus, I explored the experience of waiting on WLS following van Manen's guide for phenomenological reflection and writing. Seven persons waiting for WLS were recruited for participation. I gathered experiential descriptions through phenomenological interviews/reflections. Analysis involved the practices of phenomenological reductions and writing.

I drew on the philosophical writings of Alphonso Lingis on contact to explore the relational experiences of persons waiting on WLS. Lingis described contact with the other as an ethical engagement, a relational space where one acknowledges another for all of their pain, suffering, desire, joy and so on. Contact occurs when I truly see the other, when I meet their gaze and connect with their human---ness. Contact is a tactful encounter. Waiting for WLS shows itself through the wait for contact. Persons waiting for WLS sought contact in relationships at the clinic (staff, clinicians, other patients) and beyond (family, friends, colleagues, support groups and so on). Nevertheless, contact as described by Lingis, was frequently partial or completely unrealized. Through this presentation I will explore the experiences of contact as they relate to the wait for WLS and reflect on the possible implications for clinical care (and other caring) practices.

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### **Waiting For the Magic: Reflections on a Grounded Theory Study**

Virginia Dickson-Swift

*La Trobe University*

Doctoral candidates embark on a journey that takes them through a maze of different theoretical and practical challenges. One such challenge involves engaging with and understanding theoretical concepts in order to produce a piece of research that is theoretically rich and useful. In addition to this, many qualitative researchers are adopting grounded theory methodologies in their research and in doing so are often involved in developing theory that will be used by others. Embarking on a grounded theory study requires that the researcher has a sound understanding of both the method and the process. One of the central tenets of grounded theory is that the theory should emerge from the data collected

during data analysis. This emergence is often depicted as if it happens quite magically. This article reflects on the journey of a doctoral student as she grappled with epistemology and ontology, searched for a paradigm, grasped methodology and waited for the magic in her grounded theory study to appear. It details her experiences as she moved from being 'theory shy' to 'theory smart'.

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### **'What's the Point of Learning about Qualitative Research?'**

Julia Williams

*University of Hertfordshire*

Frequently in undergraduate paramedic programmes, the evaluations of the research modules contain comments from students questioning the need for this material indicating that there are 'more important' modules (usually skills based) that they would prefer to focus on. In particular, qualitative research is targeted, often being described as easier than quantitative approaches as, after all, 'anyone can do qualitative research, can't they?'

Drawing on background research undertaken in preparation for writing chapters on qualitative research in 'The paramedic's guide to research: an introduction' (2012), this presentation focuses on what educators can do to help students understand how qualitative research can contribute to healthcare research and ultimately impact on patients' experiences/outcomes.

Although data presented comes mainly from work with paramedic students, the presenter has experience of teaching research methods to students from other disciplines including radiography, dietetics, physiotherapy, nursing and midwifery, and she suggests these findings are transferable to all of these professions.

Consideration will be given to a) the debate surrounding integrated content vs. discrete module approach to the teaching of research; b) teaching and learning of research methods content in multiprofessional groups as opposed to uniprofessional groups, examining strengths and limitations of both.

The session complements the central theme of the QHR Conference, as we must address issues of effective teaching/learning of research methods and evidence based healthcare if we want practitioners of the future to understand that qualitative research can lead to changes in healthcare education, policy and practice.

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### **Where Do Porcupine Quills Come From? The Beginning: A Pilot Project Utilizing Winter Counts as First Nations Way of Knowing and Knowledge Translation for Health with First Nations Youth**

Deanna Bickford

*University of Saskatchewan*

Winter counts became a part of a larger program of research “Ocanku Duta Amani” or Paths to Living Well. A program that partnered with on-reserve First Nations youth to explore what health means to them and ways to improve it. The use of winter counts came as a suggestion from the community, and an Elder who had been working to inform others about this Dakota tradition.

Youth were asked to think about events in their lives that have made a contribution to their health, either positive or negative and draw events that happened along their “path to living well”. Preliminary findings showed that winter counts a) started discussion at the family level about health and what makes and keeps youth healthy, b) allowed youth to reflect on what ‘path’ their health has taken and what types of events could make it different, and, c) learn about a Dakota tradition; none of the youth had heard about a winter counts before they were introduced within the research.

This presentation will describe and discuss traditional Dakota winter counts, the process, as well as future directions.

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**“Will They Ever Learn”...If We Don’t?**

Matt Beavis

*South London and Maudsley NHS Foundation Trust*

With global recession and austerity measures biting across the healthcare delivery sector there is increased focus on outcomes, quality and efficiency. The need for organisational and individual learning to positively impact upon practice is essential with staff engagement and involvement key to embedding strategic aims within organisational culture.

Using the example of safeguarding children we discover literature suggesting decades of frustration at limited learning despite ever-increasing regulation, guidance and priority of resource afforded to staff training and review of child deaths and serious incidents.

This qualitative study used semi-structured interviews with a sample of direct care staff and managers across a large UK provider of mental health services. It concentrated on staff perceptions, knowledge and experiences of whether the organisation was a learning one, how they felt the organisation approaches learning and the success of these approaches.

The hypothesis that, given the relatively low number of child deaths and serious injury, a lack of involvement in cases reviewed impacts negatively on individual and organisational learning was tested. Participants also consistently referred to poor outcomes from mandatory, non-chosen training given competing priorities in practice.

The study sought to make staff the source of potential solution by asking them for ways in which learning methods could be better reflective of their needs and preferences. Conducting this form of qualitative research has better approached change management principles as well as shaping organisational strategic aims and arrangements, methods of organisational and individual learning; and informing formal response to current governmental consultation to statutory guidance.

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**“You Know, We Just Suck it up and Go to Work”: Ignoring Pain as a Barrier to Arthritis Management in On-Reserve British Columbia First Nations Communities**

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During the process of developing an arthritis community wellness program in collaboration with First Nations communities in British Columbia, six focus groups were conducted to determine community needs and positive pain coping methods. Focus groups were held in three communities; moderated by two members of the research team and co-moderated by community members. Two researchers independently coded the focus groups using NVivo software, employing inductive, constructivist thematic analysis.

The primary coping mechanism identified from community members was “mind over matter”, meaning perseverance through pain. Participants with arthritis felt they needed to push through their pain to meet the obligations of family, community and employers. They also felt speaking about their pain was complaining, which furthered their silence. Unfortunately, this silence often leads to frustration, loneliness and anger. Perseverance through pain is also a barrier to social support as loved ones remain unaware of their family member’s pain and therefore cannot be of service when they are needed.

Pain is a common companion to those living with arthritis, yet creating social support for pain management is difficult if it is not expressed. This presentation will discuss positive pain coping, implications of pain communication, and culturally appropriate ways to encourage communicating pain.

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